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Communication about life-sustaining therapy: insights from the Adaptive Leadership Framework

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Abstract

Objective: Effective provider and caregiver communication is central to quality care during treatment for life-threatening illnesses. The study aim was to analyze communication patterns between providers and a parent of an infant with a life-threatening disease using the Adaptive Leadership Framework, which is an activity that involves mobilizing others to adapt to a difficult situation.

Method: A secondary analysis was conducted on one case using 23 interviews with providers and mother of an infant diagnosed with Hurler's syndrome. The interviews focused on decision-making challenges in regard to the infant's treatment and were conducted over a 1-year period (pre-transplant, study entry, monthly, after a life-threatening event or substantial change in treatment and at 1-year post enrollment). Content analysis was used to identify and categorize communication patterns using concepts from the Adaptive Leadership Framework.

Results: Infant illness events and parent-provider caregiving were chronicled across a 1-year trajectory. Despite the life-threatening nature of Hurler's disease, the parent and providers did not discuss palliative care or end-of-life. The parent sought direction and answers from the providers. The Adaptive Leadership Framework suggested how communication approaches were often mismatched with the needs of the parent.

Discussion: The results of the study accentuate the need to improve communication between provider and parents about end-of-life for their child. Adaptive Leadership illuminates how providers can influence a parent's behavior when facing a challenging situation. This study suggests that Adaptive Leadership is a useful framework to guide research about healthcare communication in dealing with challenging issues.

Keywords

Adaptive Leadership, chronic critical illness, communication, infants, leadership, parent and provider relations, person-centered healthcare

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Introduction

Effective provider communication during life-sustaining treatment is essential for high quality healthcare [1-3]. When providers discuss life-sustaining treatment options, a caregiver perceives the provider to be an authoritative expert on the healthcare challenge [4]. When direction and solutions for a patient's healthcare challenge are given to caregivers, they often feel dissuaded from taking an active role in the care [5,6]. Refraining from actively participating in care can disempower the caregiver, because it assumes only the provider has the ability to solve a healthcare challenge [7]. Particularly exposed to healthcare challenges are parents of infants with Hurler syndrome. This is a complex life-threatening metabolic condition that affects vital organs and without enzyme replacement or stem cell transplantation leads to death within a few years [8]. These medically fragile infants are affected by various multisystem disease states, complex treatments and dependence on technology [9].

Parent caregivers influence their infant's outcomes through involvement in complex treatment decision-making and care [10]. The broad difficulties that parents confront during their infant's illness includes difficulties in establishing a bond with the infant in the intensive care unit [11], anxiety surrounding the infant's fragile health, concerns about losing support from the healthcare team if they reject suggestions, responsibility for performing

medical care after discharge [12], dealing with the infant's pain and discomfort [13,14], in some cases transitioning to palliative care [15,16] and making decisions about withholding or withdrawing of technological support [17]. These parents often face debilitating distress, report low satisfaction with care and lack skills to make decisions about life-sustaining treatment [10,18-20]. However, parents who actively work to adapt and overcome these healthcare challenges have better outcomes [21-22]. Providers can play a crucial role in leading caregivers to do the work required to adapt to these challenges and thrive.

Indeed, research has revealed that there is room for improvement in how providers foster the capacity of caregivers to cope when confronted by a difficult challenge [23,24]. In the complex and fast paced environment of intensive care, providers' management of the infant may exclude parental involvement [20,25]. Inadequate provider communication and lack of support make it harder for parents to confront and cope with the gravity of their child's illness [26]. Providers are in a leadership position to encourage parental adaptation and wellbeing by promoting self-reliance, resourcefulness and resilience [27]. However, existing leadership frameworks do not address the role of the parent who must perform work to adapt and effectively cope [28-32]. A more holistic leadership framework would better promote the work of parents and their adaptation to a challenging healthcare environment.

Adaptive Leadership (AL) is an organizational management framework that supports a leader's ability to mobilize people to confront difficult realities, adapt and thrive. Though it has not been widely used in healthcare, the AL framework shows promise in helping providers sustain parents as they confront a challenging reality, engage in problem-defining and problem-solving work and take responsibility for the future [33-36]. Using AL, a provider can support parents through instability and uncertainty by fostering their capacity to cope with challenges and perform difficult work that will enable them to adapt and grow [37]. Technical work, which the provider performs using expertise, differs from adaptive work, which is performed by the parent [37]. Technical work is performed in response to a technical challenge, which includes problems that are easily defined and solved with expert knowledge [38]. Technical challenges may include inserting an intravenous catheter for medication administration or the placement of a gastrostomy tube to assist in weight gain. Adaptive work is done in response to an adaptive challenge, which is a difficult reality that is hard to accept [38]. For example, a child is diagnosed with a potentially fatal disease and the parents discuss end-of-life.

The AL framework was a valuable approach to examine interviews with a parent caregiver and providers involved in the care of an infant with Hurler syndrome. Due to the complexity of challenges, AL was a suitable and insightful lens to analyze this case. The parent of this critically ill infant encountered a variety of serious challenges as a result of the infant's unpredictable health trajectory [12,13,39]. Challenges included making decisions to initiate or escalate treatments in response to a life-threatening crisis, withdrawing care and confronting severe impairment and suffering of the infant [11,12]. This case provided an opportunity to examine, through the lens of the AL framework, how providers and a mother responded to her infant's healthcare challenges [40].

Methods

The case was selected from 23 cases in a larger longitudinal, mixed method study (R01NR010548-01A1, Docherty, P.I.) designed to explore the trajectory of decision-making about life-sustaining treatment for infants with complex life-threatening conditions. This particular case, which included a mother providing care for her child with Hurler syndrome, was selected because it maximized what can be learned about Adaptive Leadership (AL) [41]. The mother had a previous child die of Hurler syndrome. Therefore she was knowledgeable about the disease trajectory and complications. She confronted the reality that advanced technological treatment was necessary to cure her child and employed adaptive work by immediately seeking the best medical care for her child. She uprooted a familiar life in a Spanish speaking United States territory and moved to a southeastern state to receive treatment for her child. Because of her challenging journey to a foreign territory and her child's acute health problems from multisystem disease states and complex treatment options [9], the AL framework provided a fitting lens to analyze these comprehensive challenges. The study was approved by the Institutional Review Board for research on human subjects.

The healthcare providers in the case included a primary nurse, an attending physician, 3 nurse practitioners, a social worker and a nurse coordinator. The legal decision-maker for the infant was the mother. The infant, who suffered from Hurler syndrome, was a patient at a large research and teaching hospital in the southeast. The semi-structured interviews occurred at study entry, monthly, after a life-threatening event and one year following enrollment. The participants were interviewed at 4 phases across a one year trajectory for a total of 23 interviews. The 'X' in the table indicates that an interview occurred one or more times. (Table 1).

Analysis

The in-depth analysis of the interviews involved reading each transcript twice to become familiar with the story and content. During the second reading, a trajectory line of the infant illness, treatment and decision-making events was created to mark the occurrence of each life-threatening event. During the third review of the interviews, the content related to challenges and treatment events were coded using concepts derived from Heifetz's Adaptive Leadership (AL) Framework.

The *a priori* concepts were selected to explore the applicability of the framework in a healthcare situation. Coded text segment were grouped in a spreadsheet by study event and were analyzed for common themes in an effort to isolate fundamental constructs and relationships

Table 1 Participant Interview and Time-point

Provider	Study Entry	Monthly	Post Life-Threatening Event	Post One Year
Primary Nurse	X			
Attending	X		X	X
Mother	X	X	X	X
Nurse Practitioner A	X			
Nurse Practitioner B			X	
Nurse Practitioner C				X
Nurse Coordinator	X			
Social Worker	X		X	X

Table 2 Adaptive Leadership Concepts [27]

Adaptive challenge	Gap between current value and difficult reality; requires change to thrive in new environment
Adaptive work	Addressing a difficult reality or conflict that requires change
Deploying yourself	Deliberately managing your roles, skills and identity
Traditional Leadership	Formal authority provides technical solution to challenges; patriarchal provider
Work avoidance	Displacing responsibility to restore equilibrium at the cost of confronting an adaptive challenge
Technical challenge	Problem that can be diagnosed and solved within a short time by applying routine procedures
Technical work	Applying known methods/procedures to a problem
Adaptive Leadership	Mobilizing and supporting others to confront a difficult reality, adapt and thrive

[42]. The mother and providers' assessments of events were examined for congruity. The data reduced in the spreadsheet were re-examined for correspondence to AL concepts [42]. The terms traditional leadership and Adaptive Leadership applied to provider behaviors; the terms technical and adaptive challenges applied to a situation and the terms technical and adaptive work applied to an action. The 8 *a priori* concepts from the AL framework included: technical challenge, technical work, adaptive challenges, adaptive work, traditional leadership and Adaptive Leadership. Two additional AL concepts emerged from the data during the coding process: deploying yourself and work avoidance [27]. This required a fourth review of all the interviews to ensure that all data were coded for the new concepts.

Results

The focus of this case was Lucy, an infant with Hurler syndrome and the communication approaches between her mother and the healthcare providers across one year of treatment. The temporally ordered case narrative focused on Lucy's life changing medical events as Maria, her mother, struggled to be optimistic and resilient. As the story unfolded, a gap between Maria and the providers' values was revealed and prevented a discussion about the possibility of Lucy's death. To ensure a systematic analysis of the results, the ordering of concepts portrayed in the story corresponded to the ordering of concepts in Table 2. The passages and quotations provided in the results are samples of text that reflected AL concepts [42,43].

Lucy's story began in a pacific island, before her conception, when her parents and brother learned Lucy's older sister, Fiona, had Hurler syndrome. Due to the lack of medical resources in their locale and relative uncertainty about the prognosis of Hurler, Fiona did not receive treatment until she was 3 years of age. The treatment was difficult for Fiona's little body to handle and physically and emotionally exhausting for her parents. Hopeful anticipation for a cure quickly abated when Fiona suffered respiratory complications caused by the treatment and she died. A year passed and much to her surprise, Maria became pregnant with Lucy. Maria and her husband were resolute to continue with the pregnancy and did everything possible to ensure that this child would have the best possible care. Maria asserted:

> "There was no chance of having an abortion…We knew that she was there and she was gonna come out no matter what and we were gonna love her no matter what."

Maria understood the disheartening possibility of having another child with Hurler; however, that possibility did not dissuade her from confronting a difficult reality and adapting to it. Having another child with a life-threatening illness was not what Maria or her husband expected, but Maria did not balk at accepting this hurdle. This situation was an *adaptive challenge* because it demonstrated a gap between the parents' current expectations and a difficult reality and required change to thrive. The hope for a healthy baby was overcome by the reality that Lucy had Hurler syndrome. Maria wanted Lucy, but did not wish to experience the death of another child. Maria responded to this adaptive challenge by performing *adaptive work.* She implemented adaptive work by courageously confronting

the adaptive challenge and continued with her pregnancy. Even though her child's prospects of survival were bleak, Maria educated herself about the disease and began preparing for the difficult challenges Lucy would confront.

Maria's resolution and persistence were echoed in her decision to guarantee Lucy received advanced treatment specific to Hurler syndrome. She applied what Heifetz identified as *deploying yourself* by deliberately and proactively managing her role, skills and identity as a mother [27]. Maria and her husband collected information about the disease and searched for facilities that provided innovative care. Nothing would stop Maria from this task, including a journey to the United States. Maria and Lucy traveled to a hospital in the southeast, which offered a chance to cure Lucy's disease by means of a stem cell transplant. Maria's sacrifice for her daughter involved leaving home and traveling to a foreign territory. The adaptive work she performed encompassed identifying what needed to change and what needed to be preserved to enable her to thrive [38]. Maria quit her job and embarked upon a long uncertain journey that required her to be away from her husband, her son and her extended family for almost a year. The financial constraints and cultural barriers which presented themselves to Maria were but a few obstacles she overcame. She sacrificed everything she knew and loved for the hope to cure her daughter.

After her courageous journey to the United States and acclimation to a new environment, Maria's self-managing adaptive skills began to wane. Maria described how the providers took charge of her daughter's care. Maria was eager to initiate the experimental treatment and welcomed the leadership and direction which the medical team provided. She relinquished her adaptive capacities and eagerly heeded the direction and authority of the providers. The formal authority exhibited by providers, is synonymous with *traditional leadership* and occurred when a provider took responsibility for solving problems with medical expertise. Maria's dependence on the providers to take responsibility of care and deliver technical solutions is illustrated in the following quote:

> "Talking to Dr. Johnson I was so desperate and worried, she was telling me how things are gonna be going and I was like, ok, let's start right now. And that did happen. He [Dr. Johnson] made it happen that way. I was convinced that I was in the best place…everyone calling you saying this is what we can't do; this is what we can do. It's so important, that people that work for Dr. Johnson actually calling [me] and just making sure that everything is going the way it should go."

Even though Maria had a previous child die from the disease, she had confidence the providers would heal her daughter. The authoritative role of the providers gave Maria assurance that everything would 'go the way it should.' She welcomed having the providers tell her what to do and this protected Maria from having to confront difficult decisions. Maria's view of the providers as traditional leaders who possessed expertise and authority, replaced her need to take an active role in her daughter's care. The possibility that Lucy could die was eluded and a discussion about end-of-life never transpired. Her perception of the providers as traditional leaders with technical solutions precluded her from accepting that death was a significant risk. The providers indirectly created an environment that encouraged Maria to depend on their expertise to heal Lucy, instead of fostering Maria's adaptive capacity to confront a difficult reality.

Knowing Lucy's older sister had died of the same disease, Lucy's physician was keenly aware of the morbidity and mortality risks that she faced. Similar to her sister who died, Lucy exhibited symptomatic facial features and spinal curvature from the disease. An interview with the physician conveyed his acknowledgement of the acute challenges and mortality risk a child with Hurlers confronts.

> "Hurlers by definition is a very serious disease; every single day is important - (IQ changes *etc*.); with transplant (stem cell) there is a 20% chance of dying within the first 6 months just because of the side effects of the chemotherapy; I think that it's a pretty bad disease...it is a very crippling disease. You cannot say that it (transplant) is completely curative."

The nature of Hurler syndrome, as depicted by the physician, presented an adaptive challenge because of the uncertainty that treatment caused comorbidities and may not improve Lucy's health. The possibility of Lucy not surviving the transplant was very real. A gap existed between hope for Lucy's survival and the reality that death could occur. To face this harrowing reality and adapt to the possibility that Lucy may die required Maria to perform adaptive work. Initiating a discussion about end-of-life would address an adaptive challenge and was essential to improving care. However, the physician appeared to approach this as a technical challenge and delayed discussion. The physician did not address the adaptive challenge, but avoided confronting Maria with a difficult discussion. The following quotation from the physician demonstrated *work avoidance*:

> "Usually we do not discuss advanced directives in young kids...we do not discuss it up front...it's a programmatic thing...if we think there are not complications then we have just discussed this without any meaning...you're afraid it might dash their hopes if you bring it up at the very beginning."

The physician asserted that the possibility of death was not openly discussed with Lucy's mother. There was a need for an end-of-life discussion, but it would not be initiated unless death was imminent. By not discussing this possibility, the providers and mother were avoiding the responsibility of preparing for death. Avoiding the discussion of death displaced accountability and impeded progress in confronting an adaptive challenge. By employing *work avoidance*, the physician displaced the responsibility to discuss end-of-life in order to maintain equilibrium [38]. By not mobilizing Maria to perform adaptive work, the physician sacrificed preparing the mother for end-of-life to avoid conflict. Instead of exercising Adaptive Leadership, the physician exercised

traditional leadership, which provided care as an expert instead of an adaptive leader.

Lucy's situation was grave and at times required Maria to perform adaptive work, but events of Lucy's illness were also *technical challenges* amenable to *technical work.* This occurred when a problem was diagnosed and solved by medical expertise [38]. In the following passage, the nurse coordinator conceded that Lucy would receive a higher level of care if her condition was reversible. This provider identified a technical challenge, which is a problem that can be solved within a short time frame, by applying established procedures and amenable to management of routine processes [44].

> "If a child becomes very sick and needs care that we can't provide on the Bone Marrow Unit we would transfer a patient to the Intensive Care Unit. If there's an event that causes her [Lucy] to need intensive care that we know is reversible, that we know is temporary, we're gonna take care of her, we're gonna do it…"

The nurse coordinator appropriately addressed a technical challenge with technical work. Transferring Lucy to an Intensive Care Unit would effectively solve the challenge. This was a technical challenge, because it was temporary and reversible with a known solution amenable to medical expertise.

If Lucy's condition became irreversible, the nurse practitioner affirmed that the team would have a discussion with the mother. A discussion about end-of-life would have illustrated Adaptive Leadership because it demonstrated a provider mobilizing Maria to engage in a difficult conversation, but instead she uses work avoidance.

> "Sometimes we do have those kinds of conversations [end-of-life], but we haven't had that kind of conversation with Lucy's family. If something was to happen to her and she was to get sick, then we would obviously start talking more, but no we haven't."

The nurse practitioner conceded she did not plan to discuss end-of-life unless Lucy was in an irreversible condition. Lucy had a life-threatening illness, yet the provider concluded she was not yet sick enough to discuss end-of-life with Maria. To maintain equilibrium and avoid causing Maria distress, the provider did not discuss end-of-life. However, this hindered Maria from adapting to a difficult reality and preparing herself for the possibility that Lucy may require palliative care.

The social worker described her role as a provider that supports others to cope with a difficult reality and adapt, which embraces the idea of *Adaptive Leadership.* The social worker assigned to Maria and Lucy affirmed that a gap often existed between what a provider expected and reality. According to the social worker, her role differed from the role of a physician because the social worker's aim was to support the family during a challenging time so they could adapt and cope [44].

> "The physician's goal is to cure these children and that's a pretty lofty goal sometimes. That's great for me if that happens and these children are cured...but my goal is to let these families know that they don't have to walk this path alone. Whatever that path will be, if it's a path towards ending care, and helping them prepare for death, all of those are my job and if I can help them with whatever bridge they need to cross, then I'm still being helpful and I don't have to have a cure to feel that I've succeeded."

The attributes the social worker used to depict her role were analogous to qualities of an Adaptive Leader. She described the importance of supporting and mobilizing a family through a sustained period of disequilibrium [27]. An Adaptive Leadership capacity is reflected by the goal of helping families confront a difficult reality and supporting them to adapt to a challenging situation.

The interviews contained examples of 8 AL concepts. All interviews contained noticeably more examples of providers acting as traditional leaders instead of adaptive leaders. When technical problems existed, providers appropriately offered a solution based on experience and expertise. However, when an adaptive challenge existed, the providers did not employ Adaptive Leadership. The provider communication approaches were mostly that of a traditional leadership using expertise and authority to solve a challenge. Even though Hurler syndrome is a life-threatening disease with a poor prognosis, communication was only focused on interventions and cure, which deferred end-of-life discussions and prevented Maria from taking an active role in Lucy's care.

Case study research strategies, particularly the use of multiple participant perspectives, helped address the study purpose [45] of evaluating the Adaptive Leadership framework in a challenging healthcare situation. This research provided insight into the leadership approaches of multiple providers, which offered a rich source of data. However, the mother and critically ill infant was one case analysis that provided data from a single caregiver. This limits the generalizations that can be made. Case study methods inherently require subjective and interpretive elements, but with proper procedural rigor that was implemented these elements should not diminish the value of the method [46]. Providing a different context and perspective, by evaluating multiple parents in different healthcare situations would increase the trustworthiness of this research and offers direction for future studies [47].

Discussion

Due to the challenging nature of an infant undergoing experimental treatment for a complex life-threatening illness like Hurler syndrome, healthcare providers at times needed to act as adaptive leaders to assist Maria in facing the possibility of end-of-life. The data provided an exemplar of communication patterns between the providers and mother that demonstrated providers employing technical fixes to maintain equilibrium [27]. At times, Lucy's life-threatening condition required an adaptive leader that guided Maria to adapt to a difficult reality. However, the data suggested that the mother and providers perceived all of Lucy's healthcare challenges within a

technical context. When an adaptive challenge arose, the providers acted as traditional leaders and implemented technical work. This reinforced Maria's expectation that Lucy's challenges were amenable to medical interventions. But Maria's adaptive challenges were not addressed.

It is interesting to note that Maria initially exercised adaptive capacities and performed adaptive work prior to arriving at the hospital. Maria's capacity for adaptive work began to diminish as providers directed Lucy's care and employed technical fixes for all healthcare challenges. When an adaptive challenge arose, the providers acted as technical experts. The possibility of and preparation for death required a provider to act as an adaptive leader who would mobilize Maria to openly and honestly discuss end-of-life and take an active role in Lucy's care.

An interview with the physician who discussed Lucy's prognosis revealed that even with a transplant Lucy had an arduous journey to recovery fraught with uncertainty and potentially fatal obstacles. Provider communication approaches conveyed characteristics of traditional leadership and shaped the nature of communication with the mother. The providers did not address Maria's adaptive challenges by mobilizing Maria to adapt and thrive. The social worker described her job with qualities similar to an adaptive leader; however she did not exercise Adaptive Leadership. No provider discussed end-of-life, even though the infant suffered a life-threatening illness. Adaptive Leadership may have been difficult for providers to employ because it can create conflict and discomfort [48] when upsetting topics are discussed. Conversations about life-sustaining treatment could have caused distress because it required asking tough questions about end-of-life [27].

The interview data showed that both the mother and providers, excluding the social worker, identified themselves as experts who provided solutions and fixed problems. Discussing death was not an option that was entertained by the healthcare providers or mother. This is problematic because it prevented Maria from receiving holistic quality care. The case demonstrated how providers can provide technical fixes for problems amenable to medical expertise while missing relative adaptive challenges. Preparing the mother for the possibility of Lucy's death required a provider to perform Adaptive Leadership that would mobilize the mother to perform adaptive work and thrive [27].

The challenge of confronting end-of-life can create tension and must be addressed if the patient and caregiver are to adapt and thrive [4]. Employing only technical work instead of adaptive work prevented the mother from having an end-of-life discussion. Providers are in crucial positions to encourage caregivers to acquire new beliefs and accept difficult realities while maintaining them through periods of disequilibrium. Providers who mobilize caregivers to successfully adapt to a challenge will enable them to thrive [27].

Conclusion and implications for nursing education, practice and research

The longitudinal case study design was used to examine distinct viewpoints at various time points, which provided an understanding of how, why and when a change in behavior or belief occurred [49]. This is important data for establishing the validity of the Adaptive Leadership (AL) framework and applicability of using the framework as an effective leadership approach in clinical practice. The aim of this pilot case study was to gain a better understanding of how communication patterns regarding life-sustaining therapy could be viewed through the lens of the AL framework. This study provides a foundation for further research regarding specific approaches to effective communication techniques, which will enable patients to face difficult realities and adapt to change. The research can expand insights about the significance of AL in healthcare. It can add to theory development of the framework be delineating specific challenges and expanding the descriptions of adaptive approaches used by providers for patients and family members. This will also include effective approaches that providers can utilize to help patients with the decision-making process and prevent over-utilization of medical resources due to uncertainty of making a decision [37].

Further research is warranted to help guide communication when patients and caregivers are confronted by adaptive challenges. This case study suggested that care may have been enhanced if providers used AL. All providers can exercise AL by mobilizing patients to perform adaptive work. The analysis identified that providers favor taking responsibility for solving patient problems instead of mobilizing the patient to do their share of adaptive work [27]. Exercising AL will help promote end-of-life discussions and give providers the tools necessary to support their patients through life altering situations. Adaptive Leadership is an effective approach to end-of-life communication and examining the framework on a larger scale study is the next step to this research.

Acknowledgements and Conflicts of Interest

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References

[1] Alexander, S.C., Sullivan, A.M., Back, A.L., Tulsky, J., Goldman, R., Block, S., Stewart, S., Wilson-Genderson, M. & Lee, S. (2012). Information giving and receiving in

hematological malignancy consultations. *Psycho-oncology* 21 (3) 297-306.
[2] Brush, S., Budge, D., Alharethi, R., McCormick, A.J., MacPherson, J.E., Reid, B.B., Ledford, I.D., Smith, H.K., Stoker, S., Clayson, S.E., Doty, J.R., Caine, W.T., Drakos, S. & Kfoury, A.G. (2010). End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *Journal of Heart and Lung Transplantation* 29 (12) 1337-1341.
[3] Cooper, R. & Koch, K.A. (1996). Neonatal and pediatric critical care: ethical decision making. *Critical Care Clinics* 12 (1) 149-164.
[4] Biddle, B.J. (1986). Recent Development in Role Theory. *Annual Review of Sociology* 12, 67-92.
[5] Bohart, A.T. (1996). How Clients Make Therapy Work. Washington DC: American Psychological Association.
[6] Haeusler, J.M. (2010). Medicine needs Adaptive Leadership. *Physician Executive* 36 (2) 12-15.
[7] Robertson, K. (2005). Active listening: more than just paying attention. *Australian Family Physician* 34 (12) 1053-1055.
[8] Grigull, L., Sykora, K-W., Tenger, A., Bertram, H., Meyer-Marcotty, M., Hartmann, H., Bültmann, E., Beiken, A., Zivicnjak, M., Mynarek, M., Osthaus, A.W., Schilke, R., Kollewe, K. & Lücke, T. (2011). Variable disease progression after successful stem cell transplantation: Prospective follow-up investigations in eight patients with Hurler syndrome. *Pediatric Transplantation* 15 (8) 861-869.
[9] Srivastava, R., Stone, B. & Murphy, N. (2005). Hospitalist care of the medically complex child. *Pediatric Clinics of North America* 52 (4) 1165-1187.
[10] Eden, L. & Callister, L. (2010). Parent Involvement in End-of-Life Care and Decision Making in the Newborn Intensive Care Unit: An Integrative Review. *Journal of Perinatal Education* 19 (1) 29-39.
[11] Fegran, L., Helseth, S. & Fagermoen, M. (2008). A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit. *Journal of Clinical Nursing* 17 (6) 810-816.
[12] Bakewell-Sachs, S. & Gennaro, S. (2004). Parenting the post-NICU premature infant. *MCN American Journal of Maternal/Child Nursing* 29 (6) 398-403.
[13] Murdoch, M.R. & Franck, L.S. (2012). Gaining confidence and perspective: a phenomenological study of mothers' lived experiences caring for infants at home after neonatal unit discharge. *Journal of Advanced Nursing* 68 (9) 2008-2020.
[14] Reyna, B.A., Pickler, R.H. & Thompson, A. (2006). A descriptive study of mothers' experiences feeding their preterm infants after discharge. *Advanced Neonatal Care* 6 (6) 333-340.
[15] Haward, M.F., John, L.K., Lorenz, J.M. & Fischhoff, B. (2012). Effects of Description of Options on Parental Perinatal Decision-Making. *Pediatrics* 129 (5) 891-902.
[16] Docherty, S.L., Miles, M.S. & Brandon, D. (2007). Searching for "the dying point": providers' experiences with palliative care in pediatric acute care. *Pediatric Nursing* 33 (4) 335-341.
[17] O Brien, I., Duffy, A. & O'Shea, E. (2010). Medical futility in children's nursing: making end-of-life decisions. *British Journal of Nursing* 19 (6) 352-356.
[18] Donohue, P.K., Hussey-Gardner, B., Sulpar, L.J., Fox, R. & Aucott, S.W. (2009). Convalescent Care of Infants in the Neonatal Intensive Care Unit in Community Hospitals: Risk or Benefit? *Pediatrics* 124 (1) 105-111.
[19] Franck, L.S., Oulton, K., Nderitu, S., Lim, M., Fang, S. & Kaiser, A. (2011). Parent Involvement in Pain Management for NICU Infants: A Randomized Controlled Trial. *Pediatrics* 128 (3) 510-518.
[20] Franck, L.S., Oulton, K. & Bruce, E. (2012). Parental involvement in neonatal pain management: an empirical and conceptual update. *Journal of Nursing Scholarship* 44 (1) 45-54.
[21] Singer, E., Couper, M.P., Fagerlin, A., Fowler, F.J., Levin, C.A., Ubel, P.A., Van Hoewyk, J. & Zikmund-Fisher, B.J. (2011). The role of perceived benefits and costs in patients' medical decisions. *Health Expectations* 10. doi: 10.1111/j.1369-7625.2011.00739.x.
[22] O'Connor, A.M., Bennett, C.L., Stacey, D., Barry, M., Col, N.F., Eden, K.B., Entwistle, V.A., Fiset, V., Holmes-Rovner, M., Khangura, S., Llwellyn-Thomas, H. & Rovner, D. (2009). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Systems Review*, (10), CD001431.
[23] Tistad, M., Tham, K., von Koch, L. & Ytterberg, C. (2012). Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. *BMC Neurology* 12, 40.
[24] Tsui, P., Day, M., Thorn, B., Rubin, N., Alexander, C. & Jones, R. (2012). The Communal Coping Model of Catastrophizing: Patient–Health Provider Interactions. *Pain Medicine* 13 (1) 66-79.
[25] McGraw, M.P. & Perlman, J.M. (2008). Attitudes of Neonatologists Toward Delivery Room Management of Confirmed Trisomy 18: Potential Factors Influencing a Changing Dynamic. *Pediatrics* 121 (6) 1106-1110.
[26] Rajani, A.K., Chitkara, R. & Halamek, L.P. (2009). Delivery Room Management of the Newborn. *Pediatric Clinics of North America* 56 (3) 515-535.
[27] Heifetz, R. (2009). The Practice of Adaptive Leadership: Tools and Tactice for Changing your Organization and the World. Boston: Harvard Business Press.
[28] Lichtenstein, B., Uhl-Bien, M., Marion, R., Seers, A., Orton, J. & Schreiber, C. (2006). Complexity leadership theory: An interactive perspective on leading in complex adaptive systems. *Emergence: Complexity and Organization* 8 (4) 10.
[29] Uhl-Bien, M., Marion, R. & McKelvey, B. (2007). Complexity Leadership Theory: Shifting leadership from the industrial age to the knowledge era. *The Leadership Quarterly* 18 (4) 298-318.
[30] Plowman, D., Solansky, S., Beck, T., Baker, L., Kulkarni, M. & Travis, D. (2007). The Role of leadership in emergent, self-organization. *The Leadership Quarterly* 18 (4) 341-356.
[31] Uhl-Bien, M. (2006). Relational leadership: exploring the social processes of leadership and organizing *The Leadership Quarterly* 17 (6) 654-676.

[32] Ford, R. (2009). Complex leadership competency in health care: towards framing a theory of practice. *Health Services Management Research* 22 (3) 14.
[33] Heifetz, R., Grashow, A. & Linsky, M. (2009). Leadership in a permanent crisis. *Harvard Business Review* 87 (7-8) 62-69.
[34] Heifetz, R.A. & Linsky, M. (2002). A Survival Guide for Leaders. *Harvard Business Review* 80 (6) 65-72.
[35] Adams, J.A., Bailey, D.E., Anderson, R.A. & Galanos, A. (2012). Adaptive Leadership: a novel approach for family decision-making. *Journal of Palliative Medicine* Epub ahead of print.
[36] Bailey, D.E.J., Docherty, S., Adams, J.A., Carthron, D.L., Corazzini, K., Day, J.R., Neglia, E., Thygeson, M. & Anderson, R.A. (2012). Studying the Clinical Encounter with the Adaptive Leadership Framework. *Journal of Healthcare Leadership* 4, 8.
[37] Thygeson, M., Morrissey, L. & Ulstad, V. (2010). Adaptive Leadership and the practice of medicine: a complexity-based approach to reframing the doctor-patient relationship. *Journal of Evaluation in Clinical Practice* 16 (5) 1009-1015.
[38] Heifetz, R., Linsky, M. & Grashow, A. (2009). The Practice of Adaptive Leadership: Tools and tactics for changing your organization and the world. Boston: Harvard Business Press.
[39] Orzalesi, M. (2010). Ethical problems in the care of high risk neonates. *Journal of Maternal Fetal Neonatal Medicine* 23 (Supplement 3) 7-10.
[40] Heifetz, R. (2009). Adaptive Leadership. Creelman Research. http://www.creelmanresearch.com/. Accessed August 21, 2012.
[41] Stake, R. (1995). The Art of Case Study Research. Thousand Oaks: Sage Publications.
[42] Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research* 1 (3) 385-405.
[43] Miles, M.B. & Huberman, A.M. (1984). Drawing Valid Meaning from Qualitative Data: Toward a Shared Craft. *Educational Researcher* 13 (5) 20-30.
[44] Heifetz, R. (1994). Leadership Without Easy Answers. Cambridge: The Belknap Press of Harvard University Press.
[45] Crowe, S., Cresswell, K., Robertson, A., Huby, G. Avery, A. & Sheikh, A. (2011). The Case Study Approach. *BMC: Medical Research Methodology* 11 (100) 9.
[46] Chelimsky, E. & Grosshans, W. (1990). Case Study Evaluations. United States General Accounting Office: Program Evaluation and Methodology Division, Washington, DC.
[47] Walshe, C. (2011). The evaluation of complex interventions in palliative care: An exploration of the potential of case study research strategies. *Palliative Medicine* 25 (8) 774-781.
[48] Heifetz, R.A. & Linsky, M. (2002). Leadership on the Line: Staying Alive Through the Dangers of Leading. Boston: Harvard Business School Press.
[49] Polit, D. & Beck, C. (2008). Nursing research: generating and assessing evidence for nursing practice. 8th edn. Philadelphia: Lippincott Williams & Wilkins.