Family-Centered Care and Children with Serious Health Care Needs:
A Review of the Conceptual and Empirical Literature for Ronald McDonald House Charities

Paula M. Lantz, Ph.D.
Katherine Hohman, M.P.H.
Valerie Hutchings, B.A.
Department of Health Policy
School of Public Health and Health Services
George Washington University
Washington, DC
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Summary

Health care quality is defined as the combination of the **structure** or the organizational infrastructure and design of the care system, the **process** of care delivery, and the **outcomes** of care (Donabedian, 1988).

In this context, Ronald McDonald Houses strive to improve the quality of family-centered care by intervening in both the structure and processes of care delivery. Although Ronald McDonald Houses do not deliver clinical care to children, by enhancing and augmenting the structure and process of the family-centered care children receive in clinical settings, the Houses have the potential to impact key psychosocial outcomes, satisfaction with care, and clinical outcomes. The Houses also have the potential to increase access to high-quality care for families who do not live near a health care facility that provides the specialty or sub-specialty care that their child needs (Penchansky and Thomas, 1981).

Ronald McDonald Houses contribute to the provision of family-centered care in multiple ways, including increasing the ability of parents to spend more time with hospitalized children, to interact with their clinical care providers, and to participate in care decisions and provision. Furthermore, they provide important opportunities for family members to receive social support from providers, other professionals and other parents who are experiencing similar medical crises with their own children. The Houses also afford parents and other family members the opportunity for quality sleep and respite from the intensity and stress of the hospital. There are no studies in the published empirical literature on the impact of a Ronald McDonald House experience on the structure, process or outcomes for child patients and their families. Nonetheless, conclusions from our review of the published literature to date suggest that Ronald McDonald Houses are likely to be providing a positive impact in the following ways:

- Providing the means by which parents have increased proximity to their hospitalized children and thus are able to play a more active role in their care in turn leads to more positive attitudes and satisfaction with the care experience.
- Having parents close and more continually present when their child is hospitalized reduces parental stress and anxiety, and can also reduce post-partum depression.
- Having parents present during medical procedures reduces parental anxiety and stress.
- Having parents close and more continually present has positive benefits for children, including reduced stress, fear and anxiety, improved sleep, and—in some studies of infants—reduced length of stay.
Interventions to increase NICU infants’ exposure to their parents and to provide family-centered care reduce stress among both infants and their parents, improve sleep among infants, increase breastfeeding, increase mother/infant bonding, and reduce health care costs due to infants’ decreased use of sedatives, narcotics and vasopressors.

Providing “normalcy” and a respite from the intensity of the hospital experience can reduce the extreme psychological stress of having a critically ill or injured child in the hospital, and can improve coping among siblings.

Parents have a strong desire to participate in their children’s health care, and interventions that provide education regarding roles and expectations can lead to increased participation in the care of hospitalized children.

Providing social support from peers and other types of coping interventions reduces stress and depression and increases knowledge and confidence, which in turn improves parental participation in the care and support of their child.

This literature review and other evidence indicates that there is a strong movement in North America, Europe and other countries such as Australia and Hong Kong towards improving the physical infrastructure of children’s hospitals to better support family-centered care. The current state-of-the-art in facility design for children’s hospitals recognizes the importance of structure—and in this case the physical infrastructure—in achieving high-quality care experiences. Importantly, many of the aspects of facility design that have been shown to be related to improved care experiences are things that Ronald McDonald Houses have been designed to provide. This includes the following:

- Facility designs that increase proximity of family members to the child in the hospital can reduce parental stress/anxiety and have positive benefits for children.
- Hospitals, especially intensive care units, are noisy places with near constant activity, which is not conducive to quality sleep for patients or their parents.
- Sleeping in the hospital, while increasing proximity to the child patients, is not conducive to quality sleep. Disruptions to sleep quantity and quality are a significant source of stress to parents with a hospitalized child, even for those in a single room that allows parents to stay overnight.
- Child patients and their families need calming and distracting spaces to reduce stress and anxiety.
- Providing stable and high-quality lodging proximal to the hospital for high-risk pregnant women can avert hospitalization and reduce health care costs.
It is clear from the conceptual and theoretical literature that health care facility design alone will not enhance patient or family experiences with care. That is, this aspect of the “structure” of care is necessary but not sufficient for supporting and delivering family-centered care. The review of the literature points to many aspects that could be tied to design elements and offerings found in Ronald McDonald Houses. Keeping families close to hospitalized infants and children is a natural fit for the Houses. Close proximity allows new mothers to be close to prenatal infants to provide critical breast milk, human touch, and connection. Close proximity allows for parents to provide comfort and a sense of normalcy to hospitalized children while having a place close by to get sleep and be well rested to better support the family.

Providing the space for children, adolescents, and families that responds to the opposing needs of privacy and social support is a unique offering of the Houses. Houses provide both private rooms and social space in the form of living rooms, kitchens, etc. And while there is a move for hospital facilities to design single unit rooms, due to space restrictions they often do not have many of the amenities found in the private spaces of the Houses or places for parent-to-parent or peer-to-peer interaction that satisfies the need for social interaction and support. In addition, hospitals tend to restrict the number of family members that can sleep in the child's room or stay for extended periods of time. The Houses provide the important opportunity for more family members, often including siblings, to remain together and to have important, frequent interactions with the hospitalized child and with each other.

In conclusion, the existing literature provides a great deal of empirical support for the important role that Ronald McDonald Houses play in the health care experience of children with serious health care issues and the ability to provide family-centered care. Ronald McDonald Houses have great potential to reduce significant sources of stress for families, including financial stressors and the stress resulting from impaired sleep. The Houses also have positive impacts on families by keeping families together, providing for some normalcy in a very foreign and intense situation, allowing more family members to be near the hospitalized child, and providing opportunities for social and psychological support from other families going through the same experience. The existing literature suggests a variety of ways that Ronald McDonald Houses may impact the structure, process and outcomes of care. However, the existing literature also contains many gaps and limitations. More research is needed that focuses on the impact of the Ronald McDonald Houses specifically and the role they play in the provision of family-centered care to seriously ill children and their families.
Recommended Articles

Based on an extensive review of hundreds of research studies, the following articles are highly recommended for Ronald McDonald House Charities (RMHC) organizational leaders worldwide to enhance the understanding of the challenges faced by those served through RMHC programs and the role RMHC plays in supporting families and children.


**Family-centered care** is an approach to health care that provides an expanded and enhanced view of how care should be provided to individual patients in the context of the strengths and needs of their families (Kovacs et al., 2006). Family-centered care is viewed as critically important in providing health care to children, especially those with serious medical conditions. In the family-centered care of children, the patient and his/her family members are fully involved with health care providers to make informed decisions about the health care and support services the child and family receive. In addition, in a family-centered approach to health care, all aspects of the structure and process of care are oriented towards supporting and involving the family in the care experience with the goal of improving quality and other important outcomes, including psychosocial outcomes, clinical outcomes, resource distribution, and patient and family satisfaction.

This report presents a review of both the conceptual and empirical literature regarding family-centered care as it pertains to children receiving care in the hospital. The goal of this literature review is to provide a comprehensive and up-to-date summary of the existing literature regarding the concept of family-centered care, its theoretical underpinnings (that is, publications that attempt to define family-centered care and its key principles or values), and the evidence-base for some of the major claims made about its benefits and impacts on children facing serious illnesses and their families.

In approaching the large task of reviewing the literature on family-centered hospital care and children, we narrowed our focus to those aspects of family-centered care that are most relevant to the role that Ronald McDonald House Charities aspires to play in the health care experience for
critically-ill children and their families. As a partner in the creation of family-centered care, Ronald McDonald Houses align with some key aspects of a family-centered care model of the health care experience. As such, this review is structured to first address the research literature that describes or documents the psychosocial, financial and other issues faced by the families of critically-ill children requiring hospitalization. Second, we summarize the conceptual or theoretical literature on family-centered care as it relates to pediatric care. Third, we review the evidence base for the relationship between family-centered care and those outcomes that have the most relevance to the Ronald McDonald House experience. This includes an international review of the research literature on the impact of family-centered care on the clinical outcomes, psychosocial outcomes, and patient/family satisfaction with the care experience. This literature review also covers the state of the research on the relationship between family-centered health care facility design and patient/family outcomes.

The methods for each of the different types of literature being reviewed varied somewhat, and will be described in each of the sections below. In summary, over 1,000 articles were identified as potentially relevant and over 100 were included this review.
II.  
The Impact of Having a Critically Ill Child on the Family

The main purpose of this literature review is to identify the research studies that have attempted to demonstrate that family-centered care and related interventions can reduce some of the psychosocial and other impacts associated with a child health crisis. In addition, there is a vast amount of research literature that documents the psychological, social and economic impact that having a critically ill child can have on a family. This is an important topic, and certainly core to the mission of Ronald McDonald House Charities. Thus, in this section, we summarize the literature demonstrating the myriad difficult challenges that families face when a child is seriously ill.

One of the first and well-documented challenges a family with a seriously ill child faces is being able to access the best possible medical care for his/her specialized needs. In many situations, the best possible medical care for a serious pediatric condition is not likely to be found at a local community hospital. Many families must travel some distance to receive superior pediatric medical treatment and a number of research studies have shown that improved outcomes for highly specialized care are associated with receiving treatment in a center that performs high volumes (Goodman, 2009; McDonald et al., 2008). However, there are many barriers that prevent families from accessing the highest quality care for their child.

A large number of studies and several literature reviews document quite extensively that having a child with an acute or chronic illness that includes hospitalization is stressful for both the child and the family (Williams, 1997; Leske, 1991). In a review of over 100 reports, Shudy and colleagues (2006) found that pediatric critical illness or injury can be extremely stressful for parents and siblings, and can hurt family cohesion. The stressors are psychological, physical, and social; and some of the literature points to long-lasting detrimental effects. Families with a seriously ill child also often face extreme financial stress, both from the costs of medical care and from the logistical costs of the hospitalization, including travel, time off from work, paid caretaking for siblings, etc. (Jacobs and McDermott, 1989; Shudy et al., 2006; DiFazio and Vessey, 2011).

A plethora of studies have found that children suffer a number of negative effects when hospitalized, including nightmares, separation anxiety, general anxiety and developmental regression (Roberts, 2010). Children placed in intensive care units have been documented to experience serious emotional and behavioral problems as a result, including sadness, apathy and withdrawal, detachment, aggression, anxiety and fears, hyperactivity, sleep and eating disturbances, and enuresis (Roberts, 2010; Koller 2008). Some hospitalized children can experience effects from the experience that are similar to those of post-traumatic stress disorder.

Family members with a hospitalized child also experience severe psychological stress and anxiety, as documented in a number of studies in a variety of countries (Wray et al., 2011; Commodari, 2010; and Kennedy et al., 2004). Child hospitalization is a very stressful event for parents and other family members, even when the hospitalization is short and/or the illness is transient (Commodari, 2010). A study of the impact of childhood cancer on Australian families (Heath et al., 2006) documented high social, emotional and financial challenges. Families with
single parents, lower household income, and greater distance from the hospital were at higher risk for negative impacts, especially financial hardship. Research by Yantzi and colleagues (2001) investigated the relationship between distance from the hospital on a number of areas of family functioning and stress, finding that distance to the hospital is associated with greater difficulties regarding relationships within the immediate family and challenges in keeping the child in the family home.

Several studies also have shown that impaired sleep is of great concern and a major source of stress for parents with an infant or child in the hospital. A study of Chinese-American parents with a baby in the ICU found that mothers reported greater sleep disturbance than fathers, and that objective sleep data shows a significant relationship between impaired sleep, higher parental stress, and higher morning fatigues (Lee et al., 2007). An Australian study by McCann (2008) further underscores that sleep deprivation is a significant source of stress for parents with a hospitalized child. Having only one child/family in a room does improve sleep quality and quantity, yet the mean hours of sleep per night still remain challenged. Stremier et al. (2008) documented that although providing overnight stay accommodations for parents allows them more involvement in the care of a hospitalized child at night, this opportunity is not without challenges. The biggest concerns among parents surveyed were being away from siblings (who are rarely allowed to stay overnight), and the poor quality and quantity of sleep that results from attempting to sleep at the hospital bedside.

Davidson and colleagues (2012) recently published a review article explaining that the cluster of stressors and adverse psychological outcomes that can be experienced by a family dealing with the critical illness of a child (anxiety, acute stress disorder, posttraumatic stress, depression and complicated grief) is now labeled as “postintensive care syndrome-family” by the Society of Critical Care Medicine. Psychological difficulties do not end when a child is discharged or when a health crisis is abated; they can last for months or longer when a family has seemingly returned to normal. Distance from the hospital increases the risk for some negative psychological outcomes. The Davidson et al. review suggests that some key preventive measures include receiving frequent information and updates in understandable language, participation in decision making, receipt of support and comfort, and promotion of adaptive coping (Davidson et al., 2012).

In summary, critically ill and hospitalized children and their family members have significant financial and psychosocial needs and pressures, which need to be prevented or addressed if they are to provide the necessary support to the sick child and to promote family functioning. Family-centered care is held up as having great potential for addressing many of the challenges and negative outcomes for families when someone—including a child—is critically or chronically ill. In the sections below, we summarize what has been published on the concept of family-centered care and we review the research literature that has evaluated the impact of family-centered care and related interventions on specified outcomes.
III.
Summary of the Conceptual Literature on Family-Centered Care

Much has been written about the definition or concept of “family-centered care” by practitioners, providers, patient advocates and researchers. As such, there are a significant numbers of journal articles, reports, pamphlets and other types of documents that attempt to define “family-centered care” and its core concepts or principles. We attempted to identify the major articles in the conceptual literature on family-centered care to provide a comprehensive summary of the range of definitions and perspectives that exist in the field as they pertain to children, particularly children who are seriously ill. Our methods here included: a) a MEDLINE® search of international, published journal articles using the search terms “family centered care” and “principles,” “conceptual model,” or “theory;” and b) an internet Google search using the same search terms. From the articles, websites and online documents identified, the sample was restricted to those focused on family-centered care in the context of children with serious or special health care needs. This search process revealed over 100 writings that attempt to define the approach of family-centered care and articulate the core principles or components of this care.

While somewhat varied, there are many themes that are consistent across the conceptual models or approaches being promoted in the research and advocacy literature on family-centered care. Below we summarize this literature by presenting the major conclusions of several prominent publications/literature reviews that attempt to provide a clear and instructive conceptual framework for family-centered care in general and for children specifically.

A seminal conceptual framework regarding access to medical care was developed by Penchansky and Thomas (1981). In this framework, access to care is viewed along five different and important dimensions: availability, accessibility, accommodation, affordability and acceptability. Availability refers to the presence of qualified providers for a particular condition in a region. Accessibility is defined as how convenient a provider’s office location may be to a patient’s home and any other travel restrictions that may be a factor. Accommodation considers the office hours, wait times and ease of contacting one’s provider when needed. Affordability depends on health insurance coverage, out of pocket costs and other financial factors related to receiving care. And, finally, acceptability has to do with the cultural relevance and appropriateness of the care received and the environment in which it is provided. The 5 A’s of Access framework, in an effort to view access to health care as more than geographic or financial access, is an important foundation on which the concepts patient- and family-centered care have been built.
**Models of Family-Oriented Health Care Delivery**

In an attempt to elucidate family-centered care, Espe-Sherwindt (2008) contrasts four general models for the provision of health care to children in the context of their families:

- **Professionally-Centered Model.** Professionals are the experts who determine what the child and family needs and how to meet those needs. Families are expected to rely and depend upon the professional, who is the primary decision-maker.

- **Family-Allied Model.** Professionals view families as being able to implement interventions and participate in treatment, but the needs of the child and family are identified by the professionals.

- **Family-Focused Model.** Professionals view families as consumers who, with assistance, can choose among the various options identified and presented to the family by the professionals.

- **Family-Centered Model.** Professionals view families as equal partners. Treatment and other interventions are individualized, flexible and responsive to the family-identified needs of each child and family, with families as the ultimate decision-makers. Intervention focuses on strengthening and supporting family functioning.

In juxtaposing these different models of care, it becomes clear that “family-centered care” is a model in which children with health care needs are viewed not as isolated individuals but rather in the context of their families, and that there is a strong dynamic between families and the professionals providing care and service, guided by a set of values or principles that redefines the standard relationship. Below we present some prominent perspectives on the set of principles that guide the practice of family-centered care as a model of care.

**The Principles and Concepts of Family-Centered Care**

The National Center for Family-Centered Care (1989) has asserted that family-centered care “assures the health, well-being and quality of care of children and their families through a respectful family-professional partnership that honors the strengths, cultures, traditions and expertise that all involved are bringing to the mutual care of the child.” This notion of a “partnership” in the care of a child who is ill is rooted in the following principles:

- Families (including children) and professionals work together in the best interest of the child and the family.

- Everyone respects the skills and expertise brought to the relationship.

- Trust is acknowledged as fundamental.

- Communication and information sharing are open and objective.

- Participants make decisions together.

- There is a willingness to negotiate.
Based on this partnership, family-centered care does the following:

- Acknowledges the family as the constant in a child’s life.
- Builds on family strengths.
- Supports the child in participating in his/her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-centered in all settings.
- Celebrates successes.

The American College of Critical Care Medicine Task Force 2004-2005 conducted a review of the literature on patient-centered intensive care, and developed clinical practice guidelines to support patients and families in the adult, pediatric and neonatal intensive care unit environments (Davidson et al., 2007). The Task Force reviewed over 300 studies, but also reported the level of evidence in the vast majority was challenged. Based on the conceptual and empirical literature, the Task Force made 43 recommendations for support of the family in patient-centered intensive care, including endorsing shared decision-making models, family presence at rounds and resuscitation, and open flexible visitation.

The Institute for Patient- and Family-Centered Care, with the mission to work in partnership with patients, families and health care professionals to advance the understanding of patient- and family-centered care, has identified a cross-cutting set of four concepts that are core to both patient- and family-centered care. These four core concepts are as follows:

- **Respect and Dignity.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
Collaboration. Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

These concepts provide the basis for a vision that is a “profound change in the way health care provided to individuals and their families.” Health care encounters should build on the strengths of patients and their families, and strive to enhance their independence and choice while enhancing their confidence and competence.

Kuo et al. (2012) recently published a review article regarding the history of and current thinking about family-centered care. These authors acknowledge that a consensus definition of practices and actions that comprise family-centered care has not been achieved to date. Nonetheless, they also argue that “considerable agreement” has been achieved on regarding core principles, developed by groups such as Family Voices, the Maternal and Child Health Bureau, the American Academy of Pediatrics, the Institute for Patient- and Family-Centered Care. Jolley and Shields (2009) also published an extensive review of the international evolution of family-centered care, highlighting some of the other organizations outside of the U.S. involved with the dissemination of these core principles worldwide.

Kuo et al., (2012) lists the following general principles of family-centered care as being shared among most conceptual or theoretical approaches:

- **Information Sharing.** The exchange of information is open, objective, and unbiased.
- **Respect and Honoring Differences.** The working relationship is marked by respect for diversity, cultural and linguistic traditions, and care preferences.
- **Partnership and Collaboration.** Medically appropriate decisions that best fit the needs, strengths, values, and abilities of all involved are made together by involved parties, including families at the level they choose.
- **Negotiation.** The desired outcomes of medical care plans are flexible and not necessarily absolute.
- **Care in Context of Family and Community.** Direct medical care and decision-making reflect the child within the context of his/her family, home, school, daily activities, and quality of life within the community.
The American Academy of Pediatrics Committee on Hospital Care along with the Institute for Family-Centered Care, issued a joint policy statement in 2003 on “Family-Centered Care and the Pediatrician's Role.” More recently, on February 1, 2012, these two organizations issued an updated version of this important policy statement in the journal Pediatrics. These two prominent organizations define family-centered care as being “grounded in collaboration among patients, families, physicians, nurses, and other professionals for the planning, delivery, and evaluation of health care as well as in the education of health care professionals.” In turn, these collaborative relationships are guided by the following principles:

- **Respecting** each child and his or her family
- **Honoring racial, ethnic, cultural, and socioeconomic diversity** and its effect on the family’s experience and perception of care
- **Recognizing and building on the strengths** of each child and family, even in difficult and challenging situations
- **Supporting and facilitating choice** for the child and family about approaches to care and support
- **Ensuring flexibility in organizational policies, procedures, and provider practices** so services can be tailored to the needs, beliefs, and cultural values of each child and family
- **Sharing honest and unbiased information with families** on an ongoing basis and in ways they find useful and affirming
- **Providing and/or ensuring formal and informal support** (e.g., family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
- **Collaborating with families** at all levels of health care, in the care of the individual child and in professional education, policy making, and program development
- **Empowering each child and family** to discover their own strengths, build confidence, and make choices and decisions about their health

This policy statement also provides a review of the research/empirical literature that serves as the evidence base for validity of the principles and also for a set of fifteen recommendations, including the following:

- Pediatricians should actively consider how they can ensure that the core concepts of family-centered care are incorporated into all aspects of their professional practice.
- Parents and guardians should be offered the option to be present with their child during medical procedures and offered support before, during, and after the procedure.
Pediatricians should promote the active participation of all children in the management and direction of their own health care, beginning at an early age and continuing into adult health care.

In collaboration with families and other health care professionals, pediatricians should examine systems of care, individual interactions with patients and families, and patient flow and should modify these as needed to improve the patient’s and family's experience of care.

In every health care encounter, pediatricians should share information with children and families in ways that are useful and affirming. They should also ensure that there are systems in place that facilitate children and families’ access to consumer health information and support.

Pediatricians should encourage and facilitate family-to-family support and networking, particularly with families of similar cultural and linguistic backgrounds or families who have children with the same type of medical condition.

Health care institutions should design their facilities to promote the philosophy of family-centered care. Pediatricians should advocate for opportunities for children and families to participate in design planning for renovation or construction of hospitals, clinics, and office-based practices.

The Joint Commission (2010) recently published a detailed report that provides a “roadmap” for hospitals to implement patient- and family-centered care. This report offers numerous recommendations and practice examples for hospitals, and also details the current Joint Commission requirements regarding effective patient-centered communication, cultural competence, and patient- and family-centered care.

Foster, Whitehead and Maybee (2010) reviewed the global literature on family-centered care for hospitalized children, focusing on both developed and developing countries. They conclude that, regardless of country, culture, demographics or health care setting, a similar set of issues/concerns is raised by parents and providers in regard to child and family needs and experiences. While defined somewhat differently in across settings, four themes are fairly consistent in family-centered care as concept, including: 1) communication between medical staff and families is critical; 2) parents and providers need to negotiate clear roles in terms of care giving and decision making; 3) parents need physical, emotional and informational support; and 4) limited resources is a burden to implementing family-centered care for many reasons; family financial and other resource needs limits parental presence at the hospital in many countries, especially in developing countries (Foster et al., 2010).
Summary

Family-centered care, as a model of health care delivery to children, represents a significant shift from a limited focus on the biomedical/therapeutic needs of a child as defined by professionals to a more comprehensive and shared view of a child in the context of his/her family. The common principles across all definitions or conceptual models of family-centered care include the recognition of the primacy of family in a child’s life and respect for families as an integral and contributing part of the health care team.

Following these principles should lead to a variety of improved outcomes for patients and their families. Through mutual respect, collaboration, information exchange, shared decision-making, and support, the communication between families and health care professionals should be improved. Families will better understand their child’s condition and treatment options, and will be better equipped to participate in care decisions and implement/support aspects of that care. This, in turn, can enhance the quality, safety and impact of the care provided to patients, and can lead to a wiser allocation of health care resources. Family-centered care can also decrease the psychosocial stress associated with health crises and prolonged illness experiences, and can increase patient/family satisfaction with the care experience.

Theoretically, family-centered care is held up to have a positive impacts on the way in which care is delivered, the care experience for children and their families, and important health status outcomes. Given the theoretical claims of family-centered care, does the research literature demonstrate that it lives up to its promises?

In the following sections of this literature review, we summarize the state of the research literature for different types of claims made about the positive contributions of family-centered care for children with special health care needs. In organizing this review of the empirical literature, we focused on four areas that reflect key ways in which Ronald McDonald Houses make contributions to the implementation of family-centered care. These areas include: a) the impact of lodging and other accommodations that attempt to keep families close or together when a child is hospitalized; b) the relationship between family-centered care and clinical and psychosocial outcomes; c) the relationship between family-centered care and patient/family satisfaction with the care experience; and d) key issues in health care facility design.
IV. Review of Literature on Family-Centered Care and Clinical/Psychosocial Outcomes for Children with Special Health Care Needs

A. Methods

For this component of the literature review, we searched MEDLINE and PsycINFO using the broad terms “family-centered care” OR “family centered care.” We also conducted a separate review using the terms “accommodations” and “lodging” and “keeping families together.” Inclusion criteria included that studies had to be published between 1990 and early March of 2012, be in English, be conducted in a human population, and focus on children (0 to 19 years). Additionally, studies needed to be designed to assess the implementation of family-centered care or some related intervention on a clinical, psychosocial or process outcome for children with critical health care needs, focusing on in-patients settings or special needs populations. Titles and abstracts were reviewed and full-text versions of relevant citations were retrieved for further review.

Bibliographies of seemingly relevant articles reviewed to identify studies not yet identified through the above search. Additional bibliographies compiled by the Institute for Patient- and Family-Centered Care were reviewed; after title and abstract review, potentially relevant full-text articles were retrieved. All potentially relevant full-text articles were reviewed in detail to ensure a match to inclusion criteria and the overall purpose of the review—to discover how family-centered care influences clinical, psychosocial, and process outcomes.

The initial search identified over 700 articles. Based on the search criteria and topical relevance, this list was reduced to approximately 100 articles. The review of bibliographies and existing literature reviews added approximately 40 more articles. Most of the articles did not meet the criteria, primarily because they were not reporting on research investigating the impact of family-centered care on identifiable outcomes. In total, 30 articles (including several literature reviews) were included in this section of the review. Many studies discussing how family-centered care is implemented, what progress specific sites have made to make their programs or facilities more focused on families, or details of parents and staff preferences were excluded because they did not investigate the impact of family-centered care on any specific outcome.

B. Impact of Lodging and Other Accommodations to Keep Families Together

A study in 1984 documented the increasing trend in the U.S. (which continues to this day) towards ambulatory care and regionalized hospital specialty care, and the increasing need to minimize travel and lodging costs for patients and their families (Carpman, Grant, Simmons, 1984). In other parts of the world, this trend has also been pronounced. Argentina saw a movement toward the outpatient setting beginning in the 1970s that took place over several decades, and in Australia and Hong Kong this trend began in the 1990s. The regionalization of pediatric care has also been noteworthy in these countries. At the time of this study, only a small number of hospitals provided significant assistance with arranging overnight accommodations at hotels, hostels or apartments. Ronald McDonald House have played and continue to play an important role in overnight accommodations for pediatric patients and their families.
A study was conducted on the use of the Ronald McDonald House in Albany, New York for high-risk pregnant women (Dexter et al., 2004). Among the 41 women who stayed at the House instead of hospital, no adverse outcomes were experienced. Outpatient management of high-risk patient women at Ronald McDonald Houses is viewed as a clinically appropriate and cost-saving alternative for women with high-risk obstetrical complications. A similar study of a “Mother’s House” in Georgia also found that outpatient management of high-risk antepartum women in close proximity to the hospital saves money without compromising outcomes (Bivins, McCallum, and Roege, 2007).

A small Japan-U.S. comparative study of mothers using “family houses” or accommodation facilities affiliated with hospitals was conducted to better understand the psychosocial functioning of mothers. This study documented high levels of concerns regarding financial burdens, spending time with the hospitalized child, being separated from the rest of the family, and other concerns. Although there were some differences in the results across the two countries, both Japanese and American mothers reported that staying at the family house was very helpful in terms of information and social support exchanges with other family house users (Hohashi and Koyama, 2004).

A Canadian study of families traveling great distance for cancer treatment found that there are social, psychological and financial impacts on both the patient and the family associated with travel distance. This study also found that having volunteers assist with driving or other logistical issues helps to lessen the emotional impact and anxiety (Lightfoot et al., 2005).

Approximately one-third of hospitalized children in the U.S. are sometimes unaccompanied, which can increase the stress and anxiety of both the child and his/her family members. (Roberts, 2010) While this problem of unaccompanied hospitalized children may not be as prevalent in all parts of the world, a qualitative interview study (in Sweden) of what brings comfort to parents when their child is being treated for cancer revealed that parents derive the greatest comfort from being close to their child, feeling “at home” as much as possible in the hospital, perceiving their child’s strength, and receiving support from social networks. It is especially important that parents and children feel “a new normality” or as much at home as possible while going through the health crisis (Angstrom-Brannstrom et al., 2010).

Van Horn and Kautz (2007) conducted a review of the research literature in support of “family integrity” or allowing families access to their hospitalized children to promote family functioning. Their literature review has several important conclusions. First, many studies have demonstrated that being near the child patient is extremely important to parents and that there are benefits of open or liberal family visitation to patients, family members and nursing staff, although it is important to find a balance between the needs of the patients, family and nurses. Second, providing patient information to family members is extremely important to parents and has significant effects, including decreased anxiety, assisting family members in making informed care
decisions, and increasing satisfaction with care. Third, allowing family members to provide care in the hospital promotes family integrity and helps to prepare them for the care needed at home upon discharge.

Askins and Moore (2008) found similar results in their review of the literature on psychosocial support of the pediatric cancer patient. Some lessons learned from over 50 years of research regarding the psychosocial needs of these patients and their families demonstrates that the many interventions/services provided by child life specialists, including “medical play,” maintaining family ties during the hospitalization, patient and family education, and bereavement support, provide critically important psychosocial benefits. Such benefits include increased knowledge/understanding of the illness and treatment, improved coping, reduced fear and anxiety, improved communication and expression, and improved quality of life for patients, parents and siblings.

There is a significant amount of descriptive research regarding parental participation in the care of a hospitalized child. Garrouste-Orgeas et al. (2010) conducted a study to assess the opinions of caregivers, families and patients regarding participation in the care of family members in the ICU. The results showed extremely high rates of support for care participation among families, physicians, nurses and nursing assistants. Power and Franck (2008) in their review of the international literature identified 21 descriptive studies on this aspect of family-centered care, finding that parents both desire and expect to participate in their child’s health care and that their expectations regarding specific roles/care activities have changed over time. Twenty years ago, parents and providers had concerns about parents taking on care activities of a technical and coordinating nature. More recently, research shows that parents’ willingness and expectations regarding care participation has evolved, and that many parents desire to participate when they have adequate knowledge, self-efficacy and support. Power and Franck’s review also found that although nurses generally have positive attitudes towards parental involvement, there are both professional barriers and facilitators to participation in hospital care.

C. Results: Empirical Evidence Supporting the Value of Family-Centered Care

Very few rigorous studies have examined the results of family-centered care on outcomes for children or parents. A systematic review of the literature on family-centered care for children in the hospital published in the Cochrane Collaboration (Shields et al., 2008) found that no studies met the initial inclusion criteria, which were experimental or quasi-experimental study designs with before and after comparisons of family-centered care models and professionally-centered models of care for children up to age 12. Thus, a systematic review of impact studies based on evidence from strong comparative studies was not possible in 2008. In a follow-up article, Shields (2009) concluded that “(at) this stage, it is difficult to know whether using family-centered care makes a difference to a child’s and family’s health outcomes, as there is no rigorous evidence to answer the question ‘does it work?’ She also strongly argues that family-centered care is extremely promising
as an intervention, and has great relevance for the care of hospitalized children in all countries. In many developing countries or resource-poor areas, however, parents stay with their children in the hospital and/or participate in their care because there are not enough nurses and or any social workers, not because of any philosophical perspective. It is important that future research on family-centered care take cultural context and resources into consideration.

The studies identified implemented a number of different research designs. Several of the studies utilized some kind of comparison group in the study design, including some randomized trials. Each of the 14 impact studies identified is summarized in some detail below:

- A pre-post study of the implementation of a family-centered care model to a neonatal transitional care facility in Ohio found a significant impact on several clinical outcomes. The new model involved converting a traditional neonatal multi-bed unit to private living/sleeping units for families to be near and learn how to participate in the care of their babies from neonatal nurses. Improved outcomes included decreased parental anxiety, decreased length of stay, decreased rates of readmission, and decreased use of the emergency department (Forsythe, 1998).

- Two different pre-/post-test studies were conducted to assess the impact of nurse-based interventions to inform parents about their potential roles in care. Evans (1996) found that the five mothers who received instruction regarding how to administer intravenous antibiotics to their children with cancer felt capable of providing this care, but also needed continued assistance from nurses. Keating and Gilmore (1996) implemented a shared nurse/parent model that focused on roles, finding that nurses’ attitudes towards parental participation remained positive after the intervention, but that actual participation in aspects of children's care as documented in the medical notes varied.

- A randomized trial was conducted to investigate whether the presence of parents during invasive procedures on their children has an impact on the performance of the procedure, anxiety among providers, parents or children, the experience of pain, and parental satisfaction (Bauchner et al., 1996). Children were randomly assigned to have parents present or not during venipuncture, intravenous cannulation, or urethral catheterization. Having a parent present did not increase clinical anxiety or performance, and significantly reduced parental anxiety associated with procedure. However, having a parent present did not reduce the pain level reported by the child. Given that parent presence had no negative impacts, the authors recommend the parents be encouraged to be present during a number of different types of medical procedures on their children.
A quasi-experimental study evaluated the impact of parental bed space/continual presence in the PICU on parental stress levels (Smith et al., 2007). This study, conducted at two sites that transitioned to new facilities with parental rooming in the PICU, compared parental stress levels before and after the facility changes. The study design allowed the comparison of a PICU environment in which there was no bed space and parents were required to leave during rounds and shift changes, to a more family-centered environment in which one parent was allowed to sleep in the PICU and parents were allowed to be continually present. The study results demonstrated that the parents in the new facilities had significantly lower stress levels, particularly stress regarding their own role in their child’s care and stress regarding their child’s appearance.

A quasi-experimental prospective study of maternal stress was undertaken by Erdeve et al. (2009) at a hospital in Turkey. The study examined the differences in parental stress when a mother was able to remain hospitalized in a room with her infant post NICU stay compared to when the infant remained hospitalized and the mother was not. Mothers in the two groups were compared on a number of psychosocial variables, controlling for sociodemographic factors, infant severity of illness and NICU performance. Psychosocial metrics for depression, stress and feelings of vulnerability were lower among the mothers who stayed in the hospital with their infants, although these differences were not significant. However, a significant difference between the groups was that the rate of post-partum depression was lower among the mothers who stayed in the hospital.

A randomized trial of mothers of children with unexpected admissions to the hospital investigated the impact of three different interventions (audio-taped and written information about expected child behavior before/after hospitalization, parenting roles and suggestions about parent participation in care, or a combination of both) relative to a control group which received basic information about the pediatric ward and its policies. Measures of parent participation in care did not vary across the three intervention groups, while all were higher than the control group (Melnyk, 1994).

A randomized trial was conducted to examine the impact of an intervention involving oral/written information from nurses about expected post-operative behavior and parent participation in care options on clinical outcomes. The children of parents in the intervention group were able to consume fluids and be mobile sooner, and were discharged earlier from the day-surgery unit (Kristensson-Hallstrom et al., 1997).

A randomized controlled trial examined the impact of a program called Creating Opportunities for Parent Empowerment (COPE) on maternal anxiety, negative mood state, depression, maternal beliefs, parental stress, parent participation in child’s care, and child adjustment (Melnyk et al., 2004). COPE training is based on self-regulation therapy, control theory, and
the emotional contagion hypothesis, attempting to increase parents’ knowledge and understanding of the range of behaviors and emotions young children typically display during and after hospitalization, and to increase parent participation in their children’s emotional and physical care. The interventions were provided in three phases over the course of hospitalization with the last phase provided 2-3 days after discharge. Follow-up was scheduled for 1, 3, 6, and 12 months post-discharge. Nurses and mothers completed evaluations, with the nurses were blinded regarding study group. The strong study design revealed that COPE mothers were more successful in dealing with stress, and in interacting and understanding their children’s behaviors and needs. During hospitalization, COPE mothers reported significantly less parental stress, and nurses reported COPE mothers participated more in their children’s care in the PICU, compared to control mothers. Post-hospitalization, COPE mothers reported significantly less negative mood state, depression, and fewer PTSD symptoms compared to control mothers at certain follow-up assessments. Additionally, COPE children, when compared to control children, exhibited significantly fewer withdrawal symptoms, as well as fewer negative behavioral symptoms and externalizing behaviors at 12 months post discharge.

An evaluation of the March of Dimes NICU Family Support (NFS) program was conducted, which included surveys and telephone interviews with families, administrators and staff regarding the merits of the NFS program and family-centered care (Cooper et al., 2003). The eight program sites were stratified by type of site: fully-implemented NFS site (n=4), partially implemented (n=3) or not-yet implemented (n=1) NFS sites. Of the 502 NICU staff respondents, 50% were from fully implemented sites, 42% were from partially implemented sites, and 8% were from the soon to be implemented site. Fifty-three percent of all respondents, and 68% of fully implemented sites reported NICU NFS enhanced the overall quality of NICU care. Staff also reported that they either saw or anticipated NFS to result in more informed parents (81%), less stress on parents (80%), increased confidence of parents at discharge (75%), and enhanced bonding between parent and infant (74%). Parents in fully implemented sites were more likely to attend parent education hours and derive comfort from this activity, and receive parent-to-parent support. Of those in fully implemented sites, 83% indicated talking to a NFS Specialist reduced stress and made them feel more confident as parents. Furthermore, parents in fully implemented sites were more comfortable helping care for their baby (93% vs. 83% vs. 74%).

A quasi-experimental study by Byers et al. (2006) evaluated the impact of individualized, developmentally supportive family-centered care on infant physiological variables, growth, behavioral stress cues, return to sleep state, medical and developmental progress, complications, resource utilization (direct costs), and parental perception of the NICU experience. The study compared an intervention NICU room that had been renovated to reduce noise and light and allowed open visitation to a control NICU room that was similar in terms of size,
design, floor plan, staffing, and infant acuity but did not have any of the renovations and had limited visitation. In addition, nurses in the intervention NICU were educated and trained in family-centered care practices. During the 4-week evaluation period, during which the infants were evaluated every week, there were no significant differences regarding physiological characteristics, return to sleep time, or number and type of complications between the two groups. However, the intervention group had significantly lower levels of stress cues while resting, while engaged in an activity and post-activity. A post-hoc analysis found that the intervention group incurred 8% lower costs of sedatives/narcotics and 15% lower costs of vasopressors.

- A quasi-experimental, longitudinal study evaluated the impact of a nurse-led parent-to-parent support program between subjects and trained volunteer veteran parents on maternal self-esteem, family functioning, maternal-infant interaction and the quality of the home environment (Roman et al., 1995). The intervention started as soon as possible after NICU admission and continued through 12 months post discharge. The study enrolled a convenience sample of 70 mothers with infants in the NICU, and had a treatment and a control group. Maternal self-esteem scores increased from baseline to four months in the intervention group, while scores decreased for the control group. Intervention mothers had significantly lower levels of anxiety during the first four months compared to control mothers; and maternal-infant interaction was significantly higher in the intervention group compared to the control group. Family functioning scores remained similar across time and did not differ between groups.

- In collaboration with the Institute for Family-Centered Care, 11 NICUs collaborated to identify and implement best practices in family-centered care at each of the centers (Saunders et al., 2003). This study compares clinical outcomes and feeding practices in the NICU before (n=1,450) and after (n=1,572) implementation of best practices in family-centered care. After implementation, there was no difference in gestational age, birth weight, length of stay, or feeding outcomes for very-low birth weight infants. Length of stay decreased in seven centers and increased in four. The results of this study question whether family-centered care, as a philosophy for improving communication, relationships, and involvement in care, can have a significant impact on critically-important clinical outcomes for infants in the NICU.

- Hurst (2006) conducted a descriptive process evaluation of a parent-to-parent support program (PSP) in a NICU, which included three modes of interaction, weekly parent support group, hospital visitation with a veteran parent, or telephone support (Hurst, 2006). Over a two year study period, 303 families (477 individuals) used at least one mode of the PSP, with 78% using one support format exclusively, 18% using two concurrently, and 4% using all three. After discharge, 48 parents completed a survey regarding their experiences, a low response rate. Of the respondents, 92% stated they would recommend the PSP to another NICU family, and 80% "believed the PSP was an important component of newborn intensive care and that they felt supported by being able to talk with the same person from the program"
Continuity of care was important to parents, who indicated that the PSP improved this element of the NICU. In addition, 80% of the respondents indicated that interaction with veteran parents at the bedside was helpful to them in terms of managing isolation and intense emotions. Additionally, parents believed the PSP helped them become more involved with their babies’ care, learn more information about the NICU and how to communicate with staff.

A randomized trial conducted in two NICUs in Stockholm compared standard care to a family-centered approach where parents could stay continuously from infant admission to discharge. Pre-term infants were randomly assigned to one of the units. Although no differences were observed in measures of infant morbidity, those in the continuous access group had a significantly shorter length of stay (by 5.3 days) (Ortenstrand et al., 2010).

Much of the research on the impact of family-centered care has been focused on the neonatal intensive care unit. Gooding and colleagues (2011) recently reviewed the research literature on family support and family-centered care efforts in the NICU. They found that increasing opportunities for parents to stay with their infants and keeping parents informed and involving them in decision-making and care provision can have positive benefits for both the infant and the parents. Many policy changes within hospitals, including more liberal visiting hours, promotion of touch and breastfeeding, family support services, and lodging/accommodation programs, have expanded the opportunities for meaningful parental presence in the NICU. The positive effects of such interventions and programs has resulted in stronger bonds between parents and child, reduced length of stay, improved infant health indicators, and increased patient and staff satisfaction (Gooding et al., 2011). Studies have shown improved infant health in such areas as more time in sleep, decreased episodes of sleep apnea, increased time with regular heart beats, increased maturation of the circadian system, and reduced rates of infections. This review article also identified a number of issues that drive the need for family-centered care in the NICU, including parental stress and anxiety, lack of parental confidence, gaps in support for families, and an increasingly diverse population. Although not specifically mentioned in this review article, Ronald McDonald Houses play an important role in addressing a number of the challenges faced by NICU families and in implementing family-centered care in this critical care environment.

D. Limitations

The review is limited by the dearth of evidence in the published literature regarding the implementation of family-centered care interventions or programs in pediatric in-patient settings. Kuhlthau et al. (2011) conducted a review of the literature regarding family-provider partnership interventions on an array of outcomes for children with special health care needs. This review concluded that the evidence to date suggests that family-centered care is associated with improved outcomes for children with special health care needs, defined either broadly or more specifically. However,
of the 24 studies that met the review criteria and were summarized, only one (Frost et al., 2010) involved a hospital-based intervention and reported on process (rather than impact) evaluation results. Again, as mentioned above, a Cochrane Collaborative review effort conducted in 2008 found no studies on the impact of family-centered care on hospitalized children that met the review criteria in terms of strong study design (Shields et al., 2008).

This is a difficult area for research, as it is especially difficult to implement a study that utilizes a control or comparison group. Most of the studies reviewed here suffered from small sample sizes, and have issues concerning selection bias since many used convenience samples and none or non-equivalent control groups. Also, the majority of the studies reviewed were conducted in intensive care units; the generalizability to other pediatric care settings is not clear.

Additionally, it is difficult to draw clear conclusions based on a small number of studies that are examining what are essentially different interventions (Melynk et al., 2004). Family-centered care takes many different forms. Nonetheless, as family-centered care was implemented in the studies reviewed, the evidence suggests it can reduce psychosocial stress among parents, create opportunities for parents to interact more with other parents and staff, increase social support, improve parental confidence in care, and improve the overall flow of care. Family-centered care may also have positive influences on a child's illness experience, and the interactions between parent and child.
V. Review of Literature on Impact of Family-Centered Care on Patient/Family Satisfaction

A. Methods
Conceptually, there are many reasons to believe that family-centered care has a positive impact on children’s and parents’ perceptions of and satisfaction with the health care/treatment they receive. The Primary Provider Theory holds that “patient satisfaction occurs at the nexus of provider power and patient expectations” (Aragon, 2003). As such, family-centered care and its strong emphasis on a respectful, engaged and partnering relationship between families and providers holds great promise for increasing patient satisfaction with many dimensions of the care experience.

A search was conducted using MEDLINE to identify research articles on the relationship between family-centered care and satisfaction with care. Search terms included “family-centered care” OR “patient-centered care” AND satisfaction. Inclusion criteria also included a focus on children, English language, abstract included, and published 1990 through early February, 2012. Additional articles were identified by reviewing the bibliographies of articles identified through the search. In summary, this search strategy identified 55 potential articles, of which 41 were found to be not relevant because they were conceptual rather than empirical studies, they were limited descriptive studies of some type of intervention or program, or they were not actually about family-centered care.

A total of 14 research articles that present findings regarding the relationship between family-centered care and patient satisfaction in pediatric care environments were identified. Although there is a plethora of research regarding patient satisfaction with health care encounters in general, there are very few studies that have examined the association between family-centered care for children and patient/family perceptions of and satisfaction with their health care experiences.

B. Results
Among the cross-sectional studies of the association between family-centered care and patient satisfaction that do exist, the results are somewhat mixed yet mostly positive. In survey studies, there appears to be a significant and positive association between parents’ reports of higher satisfaction levels and a perceived sense of “partnership” in the care of their children. This includes the following studies and their results:

- An analysis of data from the 2005-2006 National Survey of Children with Special Health Care Needs revealed a positive and significant association between receiving adequate care coordination (a key element of family-centered care) with positive perceptions of family-provider relations (Turchi et al., 2009).

- Based on an analysis of national data on children with special health care needs, Ngui et al. (2006) found that parents reporting exposure to adequate family-centered care reported less dissatisfaction with care and fewer problems with the ease of using services. This study also found that receipt of adequate family-centered care helped to explain racial/ethnic differences in levels of dissatisfaction.
- A quasi-experimental study by Byers et al. (2006) compared an intervention NICU room that had been renovated to reduce noise/light and allowed open visitation with a control NICU room that was similar in terms of size, design, floor plan, staffing, and infant acuity but did not have any of the renovations and had limited visitation. Despite the impacts described above (lower infant stress cues and lower health care costs), parents in both groups reported a similarly high level of satisfaction with their NICU experience.

- Halfon and colleagues (2011) found that longer visits (>20 minutes) with pediatricians are associated with higher ratings for anticipatory guidance, psychosocial risk assessment and family-centered care, which in turn are associated with higher rates of parental satisfaction.

- In a study of emergency room physicians treating children with asthma, Wissow et al. (1998) found that the patient-centered physicians were more likely to be perceived of as informative, yet this was not associated with higher parental satisfaction ratings.

Non-experimental studies of satisfaction, using a variety of research designs with some type of comparison strategy, have produced mixed results:

- A study comparing maternity patients in single rooms versus shared rooms found that having a single room was associated with significantly higher levels of satisfaction in all areas that were studied, including provision of information and support, the physical environment, nursing care, education received, respect for privacy, and preparation for discharge. Having a single room after giving birth likely increases satisfaction because of the physical setting itself which allows more contact with family and privacy, the avoidance of transfers, and improved continuity of nursing care (Janssen et al., 2001).

- Dowling and colleagues (2005), in an evaluation of an intervention among families with critically ill children receiving intensive care, reported that while post-test scores did not reveal higher satisfaction levels among parents, path analysis revealed improvements in perceptions of care and communication.

- A study by Palfrey et al. (2004) found no change in satisfaction levels after implementation of a medical home family-centered care intervention for children with special health care needs.

- A longitudinal study of low-income Latino children found that parental perceptions of having a “quality medical home” were associated with several positive outcomes, including health-related quality of life and measures of school engagement (Stevens et al., 2011).

- Kuo et al., in a review of the literature, reported that several studies have found that “family-centered rounds” (e.g., introducing the family, avoiding medical terminology, involving the family in the discussion) are perceived more positively by families and can lead to increased family understanding, sense of respect from the medical team, and participation in decision making (Kuo et al., 2012).
A significant challenge for health care satisfaction research in general is that patient satisfaction surveys tend to reveal high rates of satisfaction with care experiences across settings (including pediatric care) and environments, while subjective, qualitative studies reveal significant concerns and dissatisfaction (Halfon et al., 2004). Kuo et al. (2011) suggest that “this discrepancy may reflect a ceiling effect of expectations; many parents may not know they can expect care, information, and decision-making on shared terms.” Another challenge for this type of research is how to define and measure satisfaction and all of its dimensions (Latour et al., 2005). Some approaches attempt to measure satisfaction with a number of different elements of the care experience (e.g., satisfaction with provider encounters, facilities, comfort, information provided, time waiting, feeling respected, etc.), and then aggregate from multiple questions to a more global measure of satisfaction in general. Other approaches are promoting efficiency by asking one question to measure overall satisfaction: “Would you recommend this (facility, provider, hospital) to someone else?”

Despite the challenges in measuring satisfaction and linking it to specific aspects of care, there are a number of reasons to believe that patient/family satisfaction is critically important to efforts to improve the quality of care and patient safety, and that it is an important and demonstrated outcome of family-centered care for children with special health care needs.
VI.
Review of Literature on Health Care Facility Design and the Promotion of Family Centered Care

Many elements are considered central to realizing the benefits of family-centered care, including environment-based elements in the context of facility design. This section of the literature review focuses on health care facility design elements that are purported to promote family-centered care and improve outcomes. Furthermore, this review focuses on universal design elements that could be tied to design elements found in Ronald McDonald Houses.

A. Methods
Empirical studies included in this review had to be published between 1990 and early February, 2012, be in English, be conducted in a human population, and had to focus on children (0 to 19 years). To begin, the following four databases were searched: MEDLINE, CINHAL, PsycInfo, and Scopus. Each was searched using the following key word search terms adapted for each database: “hospital design and construction” OR “facility design and construction” OR “health facility environment” OR “healthcare facility design” OR “hospital design” AND “family-centered care” OR “accommodation” OR “child, hospitalized” OR “family” OR “social support” OR “stress.” Once seemingly relevant articles were pulled, bibliographies were reviewed to identify studies not yet identified through the above search. The search was carried out between December 2011-February 2012.

Once the initial bibliography was pulled together, a preliminary review of titles and abstracts was carried out to exclude irrelevant and duplicate articles. This core set was then reviewed in detail to ensure a match to inclusion criteria and the overall purpose of the review, which was to identify research articles regarding facility design elements that promote family-centered care and improved outcomes. The initial search identified 135 articles. Based on topical relevance and the exclusion of duplicates, this list was reduced to 39 articles that were screened in more detail to ensure inclusion criteria were met. This second review added nine articles from bibliographies, and excluded 16 articles not central to the search, producing a total of 32 articles that met the inclusion criteria and were included in this review.
B. Results
Health care facility design is driven by patient populations and their very different and unique medical needs. The presentation of results below segments the findings into five different groups, based on patient population and type of care being provided.

1. Neonatal Intensive Care Unit (NICU). NICUs provide highly specialized and expensive care to the majority of premature babies born. Design aspects of the NICU have been explored in relation to their effect on the babies, mothers, and families.

NICUs in general:
- A systematic review found that design elements that facilitate contact with their infant and social support are among the high priority needs of parents who have infants in the NICU (Cleveland, 2008).
- A physical renovation to reduce noise and light issues, improve family needs around privacy, and the provision of a comprehensive care training program for staff in one NICU resulted in improved infant medical outcomes, decreasing length of stay and decreasing hospital costs (Altimier et al., 2005).
- Stress and anxiety are high for parents with children in the NICU. Thus, interventions with parents need to focus on reducing stress related to the NICU environment by providing information, normalization, and support (Miles et al., 1991).

Single family room units:
- Single family room units are found to be more conducive to family-centered care, and enhance infant medical progress and breastfeeding success over that of an open ward (Domanico et al., 2011).
- Parents whose babies received care in the single-family room facility expressed significantly improved survey responses in regard to the NICU environment, overall assessment of care, and total satisfaction score than did parents of neonates in the open-bay facility (Stevens et al., 2011).
- Among parents who moved from an open ward to private rooms, the new private room NICU was better perceived by parents to provide what was needed for their infants in regard to privacy, noise, light, secure space, access to medical staff, information and support (Carter, Carter and Bennett, 2008).
Environmental characteristics:

> There is an observable relationship among environmental stressors (light, and sound) and preterm infants physiological stress signals, and behavioral stress responses in the NICU (Peng et al., 2009).

> NICU noise influences newborns’ heart rate, indicating that these infants hear and respond to NICU sounds (Williams et al., 2009).

> The highest reported stressor in mothers with babies in the NICU was the heat intensity (Raeside, 1997).

2. Pediatric Intensive Care Unit (PICU). PICUs typically provide highly specialized care to critically ill children. And like many aspects of the hospital environment, they can suffer from high levels of noise that can have an impact on patients and staff, theoretically increasing both recovery time and stress.

Single isolation rooms:

> When comparing an open single-space unit to individual rooms the analysis suggests a possible beneficial effect of single isolation rooms in reducing nosocomial infections rate in the PICU (Ben-Abraham et al., 2002).

Environmental characteristics:

> PICU noise levels are found to exceed recommendations (Millete and Carnevale, 2003; Bailey and Timmons, 2005; Carvalho et al., 2005).

> Study findings suggest that a bedside environment with persistently elevated sound levels and abrupt increases in sound intensity throughout the night is “disruptive.” Such a disruptive nighttime environment is not conducive to restful nighttime sleep and may serve as an additional source of physiological and psychological stress for hospitalized children with cancer (Linder and Christian, 2011).

Parental factors:

• Stress scores were significantly lower for parents who utilized the parent beds in the new PICUs. New PICU environments that facilitate continual parental presence may reduce parental stress related to a child’s hospitalization (Smith et al., 2007).

• Achieving sleep is hard for parents of critically ill children in the PICU. Influences on and strategies to improve sleep include: 1) the child’s condition; 2) being at the bedside or not; 3) difficult thoughts and feelings; 4) changes to usual sleep; 5) caring for self and family; 6) the hospital environment, and 7) access to sleep locations (Stremler et al., 2011).
3. **Adolescents.** Adolescents are often cared for in areas of the hospital that are designated for children. They are a unique group whose needs are often not considered in the healthcare environment.

*Adolescent needs:*

> Recommendations from adolescents include private bedrooms and bathrooms, full-coverage pajamas, access to DVDs, continuous availability of food, and a lenient visiting policy (Blumberg and Devlin 2006).

> Adolescents identified areas for improvement, including ward facilities and measures to assist individuals to attain sufficient sleep and rest and peer support (Clift, Dampier and Timmons, 2007).

> Adolescents have definite opinions about what they want from and in a hospital environment. Participants were able to articulate what they perceive to be necessary in the ward to enable them to have private space, and they provide sufficient rationales for their reasons. The need for privacy, while in the bedroom, performing grooming activities, or using the telephone, is a recurring theme throughout the data (Hutton, 2002).

> Adolescents receiving care in a specialized adolescent cancer unit underscored the importance of being with people of their own age who had cancer (Mulhall, Kelly and Pearce, 2004).

4. **Pediatric bone marrow transplant units.**

> In assessing an open room clinic, parents indicated they preferred the environment of this clinic to traditional clinics and that the informal social support they and their children received while in the waiting room was a main strength. They had concerns with comparing their children to others and the lack of privacy (Pritchett and Buckner, 2004).

> In a study assessing the needs of siblings of bone marrow transplant recipients seven themes emerged related to how health professionals can support siblings, two of which include provide opportunities for children to meet their peers, and create a healthy hospital environment that includes having access to things like a playroom, video games, and television (Wilkins and Woodgate, 2007).
5. **General/Tertiary Care Settings**

> In a comparison of two hospitals, design features and policies had an impact on children's abilities to implement their desired coping strategies. Elements included single patient rooms, control of social interaction, inviting lounges close to room, rooms with bathrooms, enriched social support from other patients and parents, appropriate play spaces, and availability of food (Rollins, 2009).

> Mothers of children who had sustained traumatic injury express consistent financial and social stressors in addition to the need for peer support during all phases of care (Aitken, Mele, Barrett, 2004).

> Art is assumed to possess therapeutic benefits of healing for children; findings from this study indicate that nature art is the preferred type of art by children from age 5 to 17 and should be placed in children's hospital rooms in order to create a stress-reducing, healing environment (Eisen et al., 2008).

> Parents who stayed overnight with their children in the hospital experienced sleep deprivation and poor quality of sleep, reporting a mean sleep period of 4.6 hours. Sleep deprivation and poor quality of sleep is an additional stress experienced by a parent with a child in hospital (McCann, 2008).

> Nurses found that the patients preferred the garden more than the ward because it allows them to: 1) play freely and safely either alone or with peers, 2) escape from the confined ward environment into an open space where they can observe animals, and 3) gain control on their movements. As a result, the patients feel cheerful and are more agile, suggesting their cognitive functioning is restored (Said et al., 2005).

> Pediatric hematology-oncology patients and their parents reported their own perceived built environment satisfaction, which is significantly related to the quality of the objective built environment. For parents, results support the mediational hypothesis, highlighting the importance that perceived built environment satisfaction plays in psychosocial functioning and healthcare satisfaction (Sherman-Bien et al., 2011).
C. Recommendations from the Design Literature

Aspects of the physical environment and its design can have both positive and negative impacts on the children receiving care and their families. Health care facility designers are urged to consider the scientific literature that suggests that health care environments will better support coping with stress and promote wellness by providing: 1) a sense of control, 2) access to social support; and 3) access to more positive distractions and less negative distractions (Ulrich, 1991).

In 2008, Sadler and Joseph refined Ulrich’s perspective through a literature review to define what elements of the physical environment of pediatric settings impact clinical, developmental, psychosocial and safety outcomes among patients and families. The evidence-based design strategies that were identified from the pediatric setting included the following 10 elements (Sadler and Joseph, 2008):

1. Single family room NICU
2. Circadian lighting in the NICU
3. Incubator noise reduction in the NICU
4. Sound absorbing ceiling tiles
5. Space for families in all patient rooms and on all units
6. Patient and family control over privacy and environmental conditions
7. Calming music distractions before/during procedures
8. Positive distractions to reduce anxiety
9. Access to nature through gardens
10. Age appropriate play areas
11. Overall ambience and attractiveness
Health care quality is defined as the combination of the structure or the organizational infrastructure and design of the care system, the process of care delivery, and the outcomes of care (Donabedian, 1988). In this context, Ronald McDonald Houses strive to improve the quality of family-centered care by intervening in both the structure and processes of care delivery. Although Ronald McDonald Houses do not deliver clinical care to children, by enhancing and augmenting the structure and process of the family-centered care children receive in clinical settings, the Houses have the potential to impact key psychosocial outcomes, satisfaction with care, and clinical outcomes. The Houses also have the potential to increase access to high-quality care for families who do not live near a health care facility that provides the specialty or sub-specialty care that their child needs (Penchansky and Thomas, 1981).

Ronald McDonald Houses contribute to the provision of family-centered care in multiple ways, including increasing the ability of parents to spend more time with hospitalized children, to interact with their clinical care providers, and to participate in care decisions and provision. Furthermore, they provide important opportunities for family members to receive social support from providers, other professionals and other parents who are experiencing similar medical crises with their own children. The Houses also afford parents and other family members the opportunity for quality sleep and respite from the intensity and stress of the hospital. There are no studies in the published empirical literature on the impact of a Ronald McDonald House experience on the structure, process or outcomes for child patients and their families. Nonetheless, conclusions from our review of the published literature to date suggest that Ronald McDonald Houses are likely to be providing a positive impact in the following ways:

- Providing the means by which parents have increased proximity to their hospitalized children and thus are able to play a more active role in their care in turn leads to more positive attitudes and satisfaction with the care experience.
- Having parents close and more continually present when their child is hospitalized reduces parental stress and anxiety, and can also reduce post-partum depression.
- Having parents present during medical procedures reduces parental anxiety and stress.
- Having parents close and more continually present has positive benefits for children, including reduced stress, fear and anxiety, improved sleep, and—in some studies of infants—reduced length of stay.
- Interventions to increase NICU infants’ exposure to their parents and to provide family-centered care reduce stress among both infants and their parents, improve sleep among infants, increase breastfeeding, increase mother/infant bonding, and reduce health care costs due to infants’ decreased use of sedatives, narcotics and vasopressors.
Providing “normalcy” and a respite from the intensity of the hospital experience can reduce the extreme psychological stress of having a critically ill or injured child in the hospital, and can improve coping among siblings.

Parents have a strong desire to participate in their children’s health care, and interventions that provide education regarding roles and expectations can lead to increased participation in the care of hospitalized children.

Providing social support from peers and other types of coping interventions reduces stress and depression and increases knowledge and confidence, which in turn improves parental participation in the care and support of their child.

This literature review and other evidence indicates that there is a strong movement in North America, Europe and other countries such as Australia and Hong Kong towards improving the physical infrastructure of children’s hospitals to better support family-centered care. The current state-of-the-art in facility design for children’s hospitals recognizes the importance of structure—and in this case the physical infrastructure—in achieving high-quality care experiences. Importantly, many of the aspects of facility design that have been shown to be related to improved care experiences are things that Ronald McDonald Houses have been designed to provide. This includes the following:

- Facility designs that increase proximity of family members to the child in the hospital can reduce parental stress/anxiety and have positive benefits for children.
- Hospitals, especially intensive care units, are noisy places with near constant activity, which is not conducive to quality sleep for patients or their parents.
- Sleeping in the hospital, while increasing proximity to the child patients, is not conducive to quality sleep. Disruptions to sleep quantity and quality are a significant source of stress to parents with a hospitalized child, even for those in a single room that allows parents to stay overnight.
- Child patients and their families need calming and distracting spaces to reduce stress and anxiety.
- Providing stable and high-quality lodging proximal to the hospital for high-risk pregnant women can avert hospitalization and reduce health care costs.

It is clear from the conceptual and theoretical literature that health care facility design alone will not enhance patient or family experiences with care. That is, this aspect of the “structure” of care is necessary but not sufficient for supporting and delivering family-centered care. The review of the literature points to many aspects that could be tied to design elements and offerings found in Ronald McDonald Houses. Keeping families close to hospitalized infants and children is a
natural fit for the Houses. Close proximity allows new mothers to be close to prenatal infants to provide critical breast milk, human touch, and connection. Close proximity allows for parents to provide comfort and a sense of normalcy to hospitalized children while having a place close by to get sleep and be well rested to better support the family.

Providing the space for children, adolescents, and families that responds to the opposing needs of privacy and social support is a unique offering of the Houses. Houses provide both private rooms and social space in the form of living rooms, kitchens, etc. And while there is a move for hospital facilities to design single unit rooms, due to space restrictions they often do not have many of the amenities found in the private spaces of the Houses or places for parent-to-parent or peer-to-peer interaction that satisfies the need for social interaction and support. In addition, hospitals tend to restrict the number of family members that can sleep in the child's room or stay for extended periods of time. The Houses provide the important opportunity for more family members, often including siblings, to remain together and to have important, frequent interactions with the hospitalized child and with each other.

In conclusion, the existing literature provides a great deal of empirical support for the important role that Ronald McDonald Houses play in the health care experience of children with serious health care issues and the ability to provide family-centered care. Ronald McDonald Houses have great potential to reduce significant sources of stress for families, including financial stressors and the stress resulting from impaired sleep. The Houses also have positive impacts on families by keeping families together, providing for some normalcy in a very foreign and intense situation, allowing more family members to be near the hospitalized child, and providing opportunities for social and psychological support from other families going through the same experience. The existing literature suggests a variety of ways that Ronald McDonald Houses may impact the structure, process and outcomes of care. However, the existing literature also contains many gaps and limitations. More research is needed that focuses on the impact of the Ronald McDonald Houses specifically and the role they play in the provision of family-centered care to seriously ill children and their families.


IX.
Bibliography


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