# Chapter 1
# Process and Foundation

## 1.1 Growing Importance of Case Management and Care Coordination

The United States healthcare system poses risks and unnecessary expense due to fragmentation and lack of care coordination. Lack of communication, facilitation and planning for health care experiences can, at best, be confusing and at worst, fatal. One solution to weaving together necessary information with knowledge of best practice and consideration of individual preferences is care coordination. The Patient Protection and Affordable Care Act (PPACA) supports care coordination throughout descriptions of new models of care delivery and provisions for changes in quality arrived at through collaboration and coordination of care across all services and locations (PPACA 2010). Varying models of care coordination presented as components of health care reform system are in the process of testing and implementation. Change and modification will be in play as much more needs to be accomplished. The chapters of this text intend to increase awareness of care coordination and the role of the case manager in new and existing models of care. Families and healthcare professionals can benefit from understanding the professional role of the case manager, who possesses the skills and expertise to conduct and facilitate care coordination, which is integral to ensuring effective implementation of comprehensive care with its corollary improvements in efficiency and effectiveness. The importance of care coordination for children extends to the health of the family as described by Cousino and Hazen (2013) as well as Shudy et al. (2006), recognizing the physical and emotional stressors of being a family inclusive of a child with special healthcare needs.

This subject has relevance to children and families to equip them with an understanding of the definitions, key concepts, theory support, and structure of case management and care coordination. Knowledge of the benefits care coordination can provide to families is important in support of child health, family self-advocacy efforts, and for holding delivery models accountable to provide effective



J. Treadwell et al., *Case Management and Care Coordination*,
SpringerBriefs in Child Health, DOI 10.1007/978-3-319-07224-1_1

care coordination as part of health benefit coverage. Practitioners will gain from this text, an improved understanding of care coordination, the role of case management, and suggested ways to implement effective features within the systems of care in which they practice. Discussion of the growing recognition and responsibilities of care coordination under new models of care delivery, leading to expectations and future direction is included.

## 1.2 Definitions and Differences

The use of the terms case management and care coordination as well as the roles of case managers, care managers, care coordinators, health coaches, and patient navigators pose confusion to both consumers and health care professionals. The Case Management Society of America (CMSA), which is a certification entity for professional case managers, posits the definition of case management as:

> "Case management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality cost effective outcomes" (CMSA 2010).

Case managers are health care professionals who conduct the services and functions of case management and care coordination using knowledge of their specialty area combined with an understanding of the case management process. These individuals most frequently additionally hold licenses as registered nurses or social workers. Case managers may perform services independently or may hold a lead position in a care coordination team comprised of multiple people with varying roles and functions, focusing on a singular care plan of a child.

Care coordination is a responsibility of the entire healthcare delivery team. Communication and coordination with the child/family and all care providers delivering components of care to a child is both an ethical and professional responsibility of all health professionals caring for a child. There is an additional role of connection to the health care components from various sources, linking, where needed, to community and educational resources, and driving focus to the patient-centered plan of care. A case manager performs the oversight and connection of all activities to the benefit of the family and the provider team through care coordination.

The Agency for Healthcare Research and Quality (2007) defines care coordination as:

> "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care"
>
> Source: Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (http://www.ahrq.gov/clinic/tp/caregaptp.htm).

Case managers (sometimes referred to as care managers) perform the functions of care coordination independently or as part of a team due to their expertise in facilitating care across the continuum. The most important part of care coordination is maintaining the client as the central focus of care while ensuring all other participants are duly involved and informed of needs of preferences of the client. This process eliminates duplication of services and connects the family to needed services for their child. Care coordination has gained recognition in importance over recent years. As an example, the promotion of effective communication and coordination of care is one of the National Quality Forum's six priorities, chosen due to their impact on health outcomes (National Quality Forum 2013). The American Nurses Association (2012) sites care coordination as a core professional standard and competency and the U.S. Department of Health and Human Services established the importance of care coordination in its' National Quality Strategy and the Institute of Medicine has gone on record with the assertion care coordination could save up to $240 billion in healthcare system savings (2010). The National Committee for Quality Assurance (NCQA) defines care coordination as a function that "supports information-sharing across providers, patients, types and levels of service, sites and time frames."

Family Tip: Access to a case manager or care coordination services may be offered by your health care provider or you may obtain case management and care coordination services by contacting the member services number on your health insurance card by asking for case management assistance.

Healthcare Professional Tip: Health care professionals can request case management services by contacting the individual's health plan and asking for an assessment.

## 1.3 The Case Management Process

The case management process gives case managers a structural approach to assisting individuals and families through the care and habilitation process for maximum outcome achievement. The process includes identification and selection of children who would benefit from program services, assessment and problem identification, development of a case management plan, implementation and coordination of the plan, evaluation of changes in the child's needs and progress, and follow-up to extend, modify, or close the plan. This is not a linear model as re-assessments and plan adjustments result from evaluations during the course of case management for the child. The term integrated case management explains a program approach that recognizes the interconnectedness of physical and behavioral health in developing an individualized plan of care for a child. From the perspective of a whole person/family, this approach recognizes one cannot separate the interplay between medical and emotional beings their environment, and their access to health services when developing a plan to identify needs and preferences

that encompasses access, quality, safety, and efficiencies. Whether a diagnosis driven or integrated approach is used, managing complex health conditions occurs through use of evidence based guidelines and development of self-management strategies.

### 1.3.1 Identification and Selection

How does the case management team find a child needing services? Health care professionals are assessing for needs across all settings of care. Whether in the newborn nursery, during a well-child visit, or midst a hospitalization, identified needs trigger health care professionals that a child/family could benefit from care coordination support. Health care insurers identify children who for potential program inclusion by using analytic reporting on claim information. Pediatricians use developmental screening tools for proactive identification of children who might need care coordination and then refer to case managers for links to services. Screening tools can help in the assessment process. An example is the Child Adolescent Needs and Strengths (CANS) tool. The CANS captures parent/caregiver stress levels in addition to providing a resiliency picture of the child/adolescent. This is important to ensure the child and care giver(s) receive support and resources to achieve the highest level of functioning possible. Another screening tool is the Children with Special Healthcare Needs Screen which can identify areas needing further in-depth assessment (Table 1.1).

Programs for case management are most often considered voluntary. This means a request for participation is made to the child/family, explaining the available program and services as well as who will be interfacing with the family. Initial contact with a family is most often telephonic although may come in a face to face session or in written format. Care coordination staff asks for a verbal or written consent of participation from the responsible individual. Some health promotion or disease management programs are considered 'opt-out,' meaning that any person meeting the program inclusion criteria receives information and reminders or calls unless a person requests not to be included in a program.

### 1.3.2 Assessment

The initial assessment is extremely important however, can be time consuming. Expectations need to be set with families explaining the importance of this foundational activity. The individualized evaluation includes information that will outline future frequency, mode, and time of contacts and is inclusive of defining cultural and religious preferences, literacy screening, and assessment of barriers to function and treatment engagement. The goal is to obtain a comprehensive and accurate baseline describing the child across a holistic set of domains.

**Table 1.1** Tools used for pediatric assessment of special healthcare needs

| |
|---|
| Child adolescent needs and strengths (CANS): http://www.dhs.state.or.us/caf/safety_model/procedure_manual/ch04/ch4-section6.pdf |
| CSHCN screener: http://www.childhealthdata.org/docs/cshcn/cshcn-screener-cahmi-quickguide-pdf.pdf |
| Parents' evaluation of developmental status (PEDS): http://www.Pedstest.com |
| Modified checklist for autism in toddlers (MCHAT): http://www.mchatscreen.com |
| Ages and Stages Questionnaires (ASQ): http://agesandstages.com/ |

**Table 1.2** Domains of assessment

| | |
|---|---|
| Physiology | Environmental |
| Psychosocial | Health behaviors |
| Spiritual | Self-care |

The initial assessment is perhaps the most essential part of the process as it is extremely comprehensive and begins establishing the relationship of trust integral to optimal success. Assessment information is gained from a variety of sources including the child/family, current health care providers, records of past health care experiences, school educational plans (if applicable) and assessment of the community offerings of available services. Items included in the assessment cover domains inclusive of medical and psychosocial areas that best describe an individual in relation to their environment as well as questions to gauge specific needs and preferences of the child/family that may arise from cultural or spiritual beliefs (Table 1.2). The assessment does take some time so can be broken down into more than one session as needed to support family comfort (Table 1.3). Supplementing the assessment information are screening tools which may be initiated by the case manager, a primary care physician, or specialist.

### *1.3.3 Problem Identification and Care Plan Development*

The assessment information results are shared in a care planning session with the child/family creating clinical (medical/behavioral), social service, and wellness goals. Inclusion of the medical/behavioral home practitioners optimally occurs in real time or through communication by care coordination staff to create a shared care plan that is given to the child/family, the primary practitioner, and specialists or ancillary care providers as applicable. The team-created care plan creates a unified document to support coordination and consistency for service and to reach the child's goals.

The National Initiative for Children's Healthcare Quality and the Center for Medical Home Improvement held a working collaborative to develop contents and

**Table 1.3** Contents of typical assessment

| |
|---|
| Assessment of clients' health status, including condition-specific issues |
| Documentation of clinical history, including medications |
| Initial assessment of the activities of daily living |
| Initial assessment of mental health status, including cognitive functions |
| Initial assessment of life-planning activities |
| Evaluation of cultural and linguistic needs, preferences or limitations |
| Evaluation of visual and hearing needs, preferences or limitations |
| Evaluation of caregiver resources and involvement |
| Evaluation of available benefits within the organization and from community resources |
| Development of an individualized case management case management plan, including prioritized goals, that considers the clients' and caregivers' goals, preferences and desired level of involvement in the case management plan |
| Identification of barriers to meeting goals or complying with the plan |
| Facilitation of member referrals to resources and follow-up on process to determine whether the member acts on the referral |
| Development of a schedule for follow-up communication with clients |
| Development and communication of member self-management plans for clients |
| A process to assess progress against case management plans for clients |

explanation of a comprehensive care plan for children with special healthcare needs (http://www.medicalhomeinfo.org/downloads/pdfs/ComprehensiveCarePlanning.pdf). The document contains sample forms with topical areas of importance, stressing the need for a plan of care whether in paper copy format, contained on a memory stick or accessible through the internet.

> Family Tip: Families are to be included in care plan development. It is important that your family's needs and preferences are included in the document. Ask for a copy of your child's care plan and ask that revisions be made when your child's health condition changes.
>
> Health Care Professional Tip: To improve compliance with your instructions for medication, treatment and testing, share those items with the case manager to improve continuity and outcomes. The goal is use of a shared electronic care plan enabling all practitioners to see and interact with the child/family in one document.

### *1.3.4 Implementation and Coordination*

A care coordination team member employs a process of implementing activities to address barriers and prioritized goals as well as performs ongoing assessment and documentation to monitor the quality of care and services provided. During interim evaluation of the care plan, the case manager adjusts interventions based upon information drawn from the child/family and all care providers to ensure

**Table 1.4** Goal evaluation measures of patient-centered plan

| |
|---|
| Goal achievement |
| Adherence to medication/treatment regimen(s) |
| Barriers to compliance with provider appointments |
| Development of self-management skills |
| Ability of child/family recognition of signs and symptoms of worsening chronic condition |
| Nutritional and cognitive status |
| Psychosocial adjustments |
| Satisfaction with current services (equipment, professional) |
| Adequacy of school provision to meet needs |
| Understanding of emergency/disaster plan |
| Evaluation of results of education provision related to health and care access |
| Need for home visits for education or resource application |
| Consideration of transition needs |
| Existing support and communication between child/family and providers |
| Achieved links in the community setting |

goals are addressed. Case managers review and update care plans as needed based on condition changes but no less frequently than on a semi-annual basis (see Table 1.4).

### *1.3.5 Evaluation and Follow Up*

Engagement with the child/family is an ongoing process that enables the coordination team to perform reassessments and develop measurement of the child's progress in achieving current and prioritized goals. Evaluation assesses movement outlined in the plan of care and determines the impact of care coordination and care interventions on outcomes (Table 1.5). The case manager establishes, measurable case management goals, which promote evaluation of the access, cost and quality of the care provided to the child to facilitate measures of goal achievement that directly result from the case management interventions.

Reliable outcome data can serve as a basis of impact to future practice. Case managers use their goal directed patient- centered practice to not only evaluate each individual to monitor but the overall program they are delivering on a population management basis identifying patterns to maximize clinically positive, cost-effective outcomes. This program evaluation includes aggregate reporting of health outcomes, satisfaction surveys of families, cost analysis, and notes contact rate, frequency and care plan revisions. Outcomes are frequently then compared to national benchmarks such as the Kids Inpatient Database (http://www.hcup-us.ahrq.gov/kidoverview.jsp) or the Centers for Disease Control and Prevention Chronic Disease Calculator (2009).

**Table 1.5** Resources for family centered coordination approach

| |
|---|
| Teamwork and communication module PS 103<br>http://app.ihi.org/lms/coursedetailview.aspx?CourseGUID=3e37eb4a-4928-4d8b-976e-3a2a1a5f2c08&CatalogGUID=6cb1c614-884b-43ef-9abd-d90849f183d4 |
| Patient and Family Centered Care PFC 101<br>http://app.ihi.org/lms/coursedetailview.aspx?CourseGUID=8eb52137-21d7-4b30-afcd-fd781de6d6d5&CatalogGUID=6cb1c614-884b-43ef-9abd-d90849f183d4 |
| Writing the IFSP: National dissemination center for children with disabilities<br>http://ifspweb.org/ |
| Tools to foster the collaboration with patient and family advisors<br>http://www.ipfcc.org/tools/downloads-tools.html |

#### 1.3.5.1 Case Closure Criteria

Care coordination needs may resolve in situations that are time-limited or where self-management skills progress to a level of independence. Case closure may also occur due to change in insurance coverage, or due to aging into an adult system of healthcare delivery. Closure of the coordinating relationship may terminate due to a child's death or to child/family refusal to initiate or continue with services. The case manager documents the rationale for case closure as well as documentation of status at the time of close as a child may return to need services due to an exacerbation of condition or change of coverage.

## 1.4 Theories and Models of Practice for Case Management and Care Coordination

Care coordination has value for transition across services and as an organizing framework to support best practice. It is especially significant when addressing needs of children with multiple chronic conditions. According to a white paper published by the Partnership to Fight Chronic Disease, one in fifteen children in the United States has a chronic disease (Thorpe 2013).

Care coordination addresses the need for education and support of families through alignment of both treatment and communication using the structure of an evidenced-based model. In addition to elements of professional education and health system knowledge, case managers use theory and evidence-based practice to support families across the continuum of care.

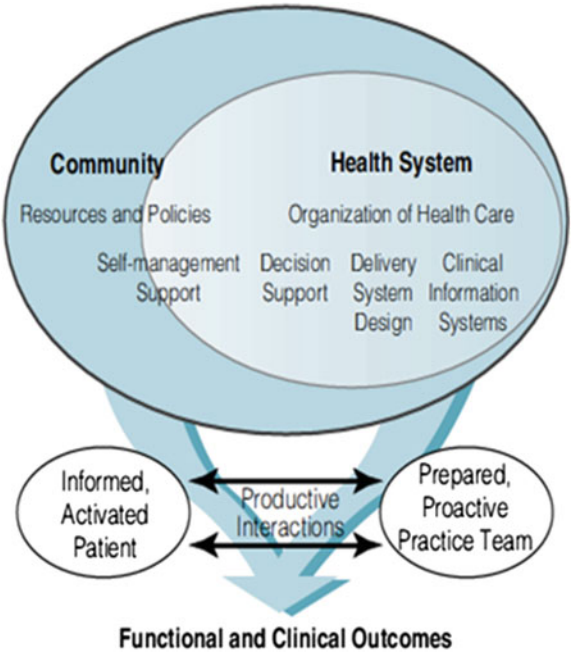


**Fig. 1.1** Wagner, EH. Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness? Effective Clinical Practice. 1998;1:2–4

### *1.4.1 The Chronic Care Model*

Wagner's Chronic Care Model (Fig. 1.1) supports an informed and activated patient (child/family) coupled with a prepared and proactive practice team. The model also acknowledges the influences of the community and the healthcare system on ultimate patient outcomes which is an important part of coordinating across school standards, neighborhood and state resources as well as navigating the health system for access and necessary services. Wagner's model is advocated in medical home models and has evidence of improved delivery of care to recipients when adopted by practitioners (Coleman et al. 2009).

### *1.4.2 Continuum of Healthcare Model*

The Case Management Society of America (CMSA) supports a continuum model of health care. Focusing on a patient centered model of case management delivery, the case management process is viewed within a circular model of financial, ethical and legal, social support and care providers. The philosophy targets optimum client wellness and function through communication, advocacy, education, resource identification, and facilitation of services to benefit the client, support system, healthcare delivery system and reimbursement (CMSA Standards of Practice for Case Management 2010).

### *1.4.3 Nursing and Social Work Theories of Case Management*

The case manager draws upon the most applicable theories to apply to any modality/specialty of need. General System's theory, exploring relationships in the universe, and critical theory, aimed at translating theory into practice, have been discussed in nursing literature as models to represent case management practice as well as nursing theories of Sister Calista Roy's theory of adaptation, and Dr. Jean Watson's Caring Science theory (Roussel 2011). Social work theory supporting case management emphasizes a biopsychosocial perspective combining knowledge from various approaches including strengths-based theory, use of learning theory, psychoanalytic theory, role theory and social network theory (Brandell 2010). The social work perspective of case management combines theory, community resources and individual needs and preferences to enable optimal clinical practice.

## 1.5 Roles

Depending on the program, diagnosis of a child, and employer of the case manager, roles may vary. The CMSA Standards of Practice describe the role of the case manager, use of evidence-based guidelines in practice, the role of minimizing fragmentation, navigating transitions of care, incorporating adherence guidelines and other standardized practice tools, expanding the interprofessional team in planning care for individuals, and improving patient safety. Another professional case management organization that focuses primarily on hospital case management, the American Case Management Association, adds the element of resource utilization into the role of case management through their Standards of Practice indicating the case manager:

> "assures prudent utilization of all resources (fiscal, human, environmental, equipment and services) by evaluating the resources available to the patient and balancing cost and quality to ensure the optimal clinical and financial outcomes (2013)."

The team approach to care coordination has as the most important member, the child/family. Case managers lead the care coordination teams due to their professional experience in assessment and collaboration. The team also may include: registered nurses, social workers, experienced parent partners, community health workers, educational specialists, and often dieticians in addition to the primary care medical home (pediatrician) and specialist healthcare professionals. Interprofessional collaboration defines the supporting culture of the care coordination team. The emphasis is on clear communication, professional accountability, shared decision making, and mutual trust across all roles on the team to result in cooperative interaction achieving improved outcomes from teamwork as opposed to a singular practitioner approach (McDonald et al. 2007).

Family Tip: The parent-to-parent model, using people who have experienced care of a child with complex health needs, is increasingly being applied in health care systems across the United States and is considered a true measure and best practice of Medical Home for Children and Youth with Special Health Care Needs (CYSHCN).

Team members conducting care coordination provide a contribution to the individuals served and to overall population health as the team scope includes the triple aim of improving the quality and experience of care as well as overall cost through developing efficiency and effectiveness through coordination (http://www.ihi.org/offerings/Initiatives/TripleAim/Pages/default.aspx). The team approach requires valuing the opinions and experience of the patient/family and other team members. The goal being to effectively communicate pertinent clinical information and treatment preferences across all professional types and organize that care to avoid duplication, support safe transfers and care transitions involved in the child's care, extending to the school and community setting as needed. Use of evidence based guidelines delivers consistency across team members and sets expectations with the family, essential when managing complex health conditions. Team training in guidelines as well as resources and culture build is necessary (Table 1.5). Care coordination requires interaction among all roles as each person on the team has a unique expertise to add to the child's success and resiliency build.

Family Tip: Movement in prioritized goals is to be addressed during each contact. The case coordination team member should create a shared expectation of communication frequency and type with the child/family/practitioner to discuss case management strategies and adjustments in the plan of care. Ask for the "who, when, and what" of contact as well as numbers to call in case of questions and emergencies.

Care Professional Tip: Team coordination supports access of families to informed professionals without repeating details of their child's information. Developing teams with shared understanding of prioritizes goals to deliver seamless coordination improves satisfaction of the care coordination team as well as families.

## 1.6 Ethics

Members of the care coordination team have an obligation to behave in a moral and ethical manner. Professionals are responsible to a code of professional conduct (nursing, social work, etc.) and team members responsible to ethical standards of their affiliated employer. Included in the concept of ethical practice and training for care coordination teams are the areas of: confidentiality, client respect, cultural competency, disclosure of conflicts of interest, and acknowledgement of self-determination. The principles of beneficence, nonmalfeasance, autonomy (respecting right to choose), and justice and fidelity (follow through) are core to care coordination practice (http://ccmcertification.org/sites/default/files/downloads/2012/41%20-%20Ethics%20issue%20brief.pdf). Ethical considerations underscore the

primary obligation to the child. Conflicts can arise for the case manager or care coordination team member due to issues of benefits, policies or regulations that require an ethical evaluation by the administrative team.

In promoting self-advocacy, the care coordination team supports family-based decision-making and self-management by providing education and promoting shared decision making across the care team. The care coordination team is responsible for advocating on behalf of the child, facilitating access, needed services, and addressing barriers/disparities that may occur during care coordination (http://www.preventioninstitute.org/tools/focus-area-tools/health-equity-toolkit.html).

Family Tip: If you feel that a bias or obstruction to needed care is present, ask for a review/appeal of your case by management staff of the entity supplying care coordination services, requesting an ethics review.

Healthcare Professional Tip: Be familiar with the Code of Ethics of your licensed profession as well as your employer. Reveal any conflicts of interest which may arise to your employer.

## References

Agency for Healthcare Research and Quality. (2007). *Closing the quality gap: A critical analysis of quality improvement strategies*. Publication No. 04(07)-0051-7. Rockville, MD. Retrieved from http://www.ahrq.gov/clinic/tp/caregaptp.htm.

American Case Management Association. (2013). *Standards of practice and scope of services for hospital/health system case management.* American Case Management Association, Little Rock, AR. Retrieved from http://www.acmaweb.org/section.asp?sID=22.

American Nurses Association. (2012, June) *The value of nursing care coordination*. Retrieved from: http://www.nursingworld.org/carecoordinationwhitepaper.

Brandell, J. (Ed.). (2010). *Theory and practice of clinical social work*, (2nd ed.). New York: Columbia University Press.

Case Management Society of America. (2010). *Standards of practice*. Retrieved from http://www.cmsa.org/Individual/MemberResources/StandardsofPracticeforCaseManagement/tabid/69/Default.aspx.

Center for Disease Control and Prevention. *Chronic disease calculator*. Retrieved at http://www.cdc.gov/chronicdisease/resources/calculator/index.htm.

Coleman, K., Austin, B., Brach, C., & Wagner, E. (2009). Evidence on the chronic care model in the new millennium. *Health Affairs, 28*(1), 75–85.

Cousino, M., & Hazen, R. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology, 38*(8), 809–828. doi:10.1093/jpepsy/jst049.

Healthcare Cost and Utilization Project. *Kids Inpatient database*. Retrieved from http://www.hcup-us.ahrq.gov/kidoverview.jsp.

Institute of Medicine. (2010). *Roundtable on value and science driven health care: The healthcare imperative: lowering costs and improving outcomes. Workshop Series Summary*. Washington, DC: National Academic Press. 2010.

Institute for Healthcare Improvement. *IHI triple aim initiative*. Retrieved from http://www.ihi.org/offerings/Initiatives/TripleAim/Pages/default.aspx.

McDonald, K., Sundram, V., Bravata, D., Lewis, R., Lin, N., Kraft, S., McKinnon, M., Paguntalan, H., & Owens, D. (2007, June). *Care coordination*. *AHRQ Publication No. 04(07)-0051-7*. Rockville, MD: Agency for Healthcare Research and Quality.

National Quality Forum, Prioritization Measures, September 16, 2013, Retrieved from: NQF.org.

Patient Protection and Affordable Care Act. (2010). Pub Law No. 111–148.

Roussel, L. (2011). *Management and Leadership for nurse administrators*, (6th Edn.). Burlington, MA: Jones and Bartlett,

Shudy, M., Lihinie de Almeida, M., Ly, S., Landon, C., Groft, S., Jenkins, T., & Nicholson, C. (2006, December). Impact of pediatric critical illness and injury on families: a systematic literature review. *Pediatrics*, *118*, S203–S218. doi: 10.1542/peds.2006-0951B.

Thorpe, J. (2013, April). Needs great evidence lacking. *Partnership to Fight Chronic Disease*. Retrieved from http://www.scribd.com/doc/137602733/Needs-Great-Evidence-Lacking-White-Paper.

Wagner, E. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice, 1*, 2–4.