Organization and Management of a Pediatric Dialysis Program

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Introduction

The organization and management of pediatric dialysis facilities has undergone many changes over the past decade. We continue to be in a rapidly changing environment with continual technological and treatment advancements. At the same time, we are experiencing new challenges with staffing shortages and government/economical restraints. Despite our rapidly changing environment, the goal of meeting patient and family needs and promoting the quality of care necessary to maintain optimal patient outcomes remains unchallenged and universal. The development of a dialysis facility program must be carefully planned and organized to meet this goal. Essential program elements discussed in this chapter include facility culture and organization, physical design, materials management, and facility operations, which includes staffing concerns, patient care services, transition, and quality improvement.

Facility Culture and Organization

The operations of a dialysis facility are diverse and complex. A caring organizational culture and an innovative management philosophy related to personnel, material management, and information organization is necessary to foster the care and services that we provide today [1, 2]. Every organization has its own unique culture. The culture is, in turn, derived from the group's shared philosophical beliefs and values. Values direct our actions and convey what we feel is commitment to the organization. Historically, the workplace was viewed as an environment dedicated solely for work. Today we know that people are happier and more productive if they can also bring their souls to work, and the workplace is seen as a place where they can grow spiritually and emotionally as well as intellectually [3]. Therefore, it is important that we create a caring, open, and positive culture. Administration must not only support these values, but they must also exhibit, encourage, and enforce them. The simple value of treating all persons with respect and dignity is the basis for caring behaviors. This

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Table 4.1 CMS facility requirements for ESRD coverage

Governing standards/conditions
Appropriate state and local licensure
Participation with ESRD networks
Governing body and appropriate affiliation agreements
Responsibilities of the medical director
Appropriate personnel policies, job descriptions, and emergency coverage
Compliance with other regulatory agencies
Personnel qualifications and competencies
Medical director: board certified in internal medicine or pediatrics, completed training program in nephrology, and has 12 months experience providing care to dialysis patients
Nurse manager: full-time registered nurse with 12 months experience in patient care and 6 months experience in dialysis
Self-care and/or home dialysis training nurse: RN with 12 months experience in patient care and 3 months dialysis experience
Technician: complete a training program specific for patient care and/or water treatment and be certified by either a state or national certification program
Dietician: be registered with the Commission on Dietetic registration and have 12 months experience in clinical nutrition
Social worker: Master's degree with specialization in clinical practice. Twenty-four months experience with 12 months experience in dialysis or transplant or who has a consultative relationship with a social worker who qualifies
Patient care issues
Patient informed of services and medical condition
Patient involved in planning for his own care
Care provided by interdisciplinary team
Receives emergency preparedness training
Rights, responsibilities, and grievance procedure addressed
Medical records present an adequate picture of care
Adequate staffing provided to meet patient needs
Infection control
Standard/universal precautions practiced
Surveillance for infections and other adverse events
Appropriate monitoring for water treatment
Serological testing and vaccination for hepatitis B virus
Data collected to reflect performance regarding quality of care delivered and compliance with requirements
Home dialysis services are at least equivalent to those provided to in-center patients
Environment
Adequate space for safety of treatment
Appropriate toxic/hazardous material procedures and precautions
Procedures and staff preparedness for emergencies

approach not only fosters creativity and innovative ideas, but also allows for failures. Caring cultures encourage flexibility and support new ideas and change. This type of organizational culture is necessary to support and provide positive outcomes and satisfaction from patients and staff [1, 3].

Standards provide the foundation for all activities within the facility. They describe the philosophy and purpose of the facility, and define the services provided. In the United States, governing standards for each facility include the "Conditions of Coverage" as mandated by the Centers for Medicare and Medicaid Services (CMS), facility specific structure standards, and facility specific policies and procedures. The CMS requirements for end-stage renal disease (ESRD) coverage are quite detailed. Specific categories addressed are summarized in Table 4.1 [4].

Structure standards are the specific guidelines for each facility. Simply stated, they are the what, where, when, why, and who questions about the facility and the services that it provides. These provide more specific direction to the staff. As mentioned previously, standards should promote a positive approach to providing health care

Table 4.2 Components of facility structure standards

Facility description and purpose
Goals and objectives
Hours of operations
Patient care criteria
Admission, transfer, discharge criteria
Care plans
Home treatments and training guidelines
Guidelines for medical follow-up
Guidelines for habilitation/rehabilitation and transition
Utilization of staff
Responsibilities of staff
Orientation/competencies
Levels/skill mix
Staffing plans and call policies
Governing rules of the unit
Safety/disaster/emergency procedures
Infection control guidelines
Confidentiality/patient rights
Supplies/equipment/medication guidelines
Visitors policy
Methods of unit communication
Interfacility communication
Staff/family communication

services. For these to be useful, they must be concise and specific. In addition, they must also promote patient and staff collaboration while emphasizing mutual respect for all parties. Common issues that are included in facility standards are summarized in Table 4.2.

The American Nephrology Nurses Association (ANNA) has also developed Standards of Clinical Practice which provide guidelines to promote excellence in patient care [5]. These standards outline five basic care goals which should be incorporated into our basic care practice. Incorporating these care goals into policies and procedures would assure that the patient and family:

- Are knowledgeable about their disease and treatment
- Receive safe and effective care
- Are free of preventable complications
- Participate as much as possible in their own care
- Attain maximal habilitation/rehabilitation

While the governing and facility structure standards are important, specific procedures must also be developed to direct clinical practice. This can be accomplished through several formats. Treatment procedures outline step-by-step instructions necessary to complete a task. Critical pathways or algorithms dictate the course of action to take in response to specific clinical situations. Both procedures and critical pathways promote the caregiver's ability to provide effective, efficient, and safe care. There are available materials that will assist with this endeavor. The National Kidney Foundations sponsors a collaborative project known as the Kidney Dialysis Outcomes Quality Initiative (KDOQI). After an extensive literature review, this initiative has resulted in the development of guidelines related to the care of the chronic kidney disease (CKD) and ESRD populations that are based on scientific evidence and clinical expertise. The guidelines are quite comprehensive and address specific issues related to dialysis treatment adequacy, access management, anemia, bone care, and nutritional management. With these guidelines serving as background material, specific procedures or protocols can be developed.

Physical Design

The basic components of a dialysis unit are established through fairly standardized codes of construction and CMS recommendations. The facility must meet appropriate codes and standards for safety and infection control. Equally as important, the physical design of the facility must allow for space that will meet current and future needs of the facility. Flexibility and efficiency are two key elements that will help accomplish this goal [6].

An effective facility design must meet the needs of the staff, as well as the patient and family. Therefore, it is important to design flow patterns that work for everyone. Patients and families must have easy access to the unit and should be able to easily navigate through the unit. Floor plans must be designed to ensure that all patients can be visibly monitored with ease, and each treatment area must be large enough to accommodate staff and equipment if emergencies should occur. Equipment and supplies must be stored in a fashion that facilitates easy access by the staff. The nursing station must be large enough to allow

for work space and use of computers so as not to violate privacy laws and confidentiality. A separate training room that is large enough to store equipment, supplies, and training aids is also essential. Special attention must be given to the design of isolation rooms. There are many stigmas associated with isolation rooms. Even the young patient understands that this area is different from the other treatment stations. Therefore, it is important that this room is as comfortable and pleasing as possible. If the patient can control any part of this environment, it is helpful. Installing lighting devices or interactive activities that can be changed and controlled by the patient is one way to make this accommodation. Providing a different décor in that room can also be helpful.

In pediatrics, there are additional environmental factors and considerations which must be incorporated into the physical design. Play therapy and music therapy have important roles. If these services are available, adequate space should be provided for these supplies and the activities. Bright colors, pictures, and other decorations are used to de-emphasize equipment and create a comfortable, relaxed setting. While the intent is to create a child-friendly environment, the atmosphere should not become visually overwhelming. It is also important to assure that the décor is age appropriate for all patients. This is challenging if the pediatric unit sees a wide age range of patients. In addition to televisions and computers, units might have exercise equipment, library carts, or other equipment and appropriate storage space, in an attempt to meet the needs of all the patients. Younger patients enjoy arts and crafts, and it is important that they be able to display their projects. Portable craft tables and rotating bulletin boards work well and can be adapted for different age groups.

While the specific treatment areas need to be esthetically pleasing, they must also be functional for the staff and meet the needs of the patients. Therefore, seating arrangements should be flexible enough to accommodate interactions, activities, and privacy as needed. Each treatment space ideally needs comfortable seating for family or visitors. Windows allow for diversion and help to foster a welcoming environment. Patient surveys have indicated that dialysis patients would like their treatment areas more "homey" and they want distractions or activities that help occupy their time. Simple things such as televisions, DVDs, music or computers can significantly decrease the boredom that arises during a treatment session, however these do require space. To promote a safe environment and reduce clutter, it is helpful for patients to have their own lockers or at least a space in which to keep their coats and personal belongings. To meet these needs in the best possible manner, it is helpful to have input from staff, patients, and family. Units that have gone through this process can also provide helpful suggestions and ideas to newly developed programs.

Materials Management

Materials management is a critical component of a dialysis unit and the responsibilities associated with it should not be taken lightly. At least one staff member should be trained in all concepts and procedures related to materials management. This includes receiving, storage, inventory control, replenishment of supplies [7], purchasing, and documentation requirements for each of these functions. Because of the variety of services provided and the wide range of patient age and sizes, the pediatric dialysis unit must maintain a large variety of equipment and supplies. Procuring these is often challenging since contracts with multiple suppliers may be needed and may prove costly. Delivery systems must be carefully selected to assure that they can accommodate small peritoneal exchange volumes or small extracorporeal circuits. And due to low demand, manufacturers frequently decrease production of pediatric-specific supplies.

All measures should be taken to minimize unit costs while maintaining treatment excellence. Unit managers must frequently reevaluate and analyze vendor contracts to maintain quality products and services in a cost-effective manner. Careful planning and tight control of inventory is important to maintain cost-efficient care. This is best accomplished with computerized inventory control systems.

Management of Facility Operations

The operations of a dialysis facility are complex and challenging. Status quo, if it ever existed, is now a thing of the past. It is of interest that while dialysis care and services have become more complex, resources and reimbursement have become more restricted. As mentioned earlier, innovative leadership which builds peer relationships and strengthens a caring culture is necessary to provide excellent services and optimum patient outcomes. While physicians direct and participate in these activities, it is the unit managers who are directly responsible for managing the day-to-day operations of the facility. The challenges facing them are often monumental and to be successful they must have the appropriate education and training for this position. Frequently, this role is filled by a nurse with excellent nursing skills but little management training, who has been promoted into the position. Assuming this expanded role and responsibilities without adequate education, resources, or support is a setup for failure. To be successful and to meet the goals of the facility, managers must have a good foundation in management practice and a supportive mentor so they can continuously develop leadership skills. A study given to 300 American Organization of Nurse Executives identified the skills necessary to accomplish the duties of a manager. The most important skills identified were effective communication and decision making. Additional skills that ranked high included: effective staffing strategies, performance evaluation, counseling, team-building, delegating, conflict resolutions, change process, and problem solving [7]. Results from a Gallup Organization report indicated that the single most important variable in employee productivity and loyalty is the quality of the relationship between employees and their direct manager [8]. This was more significant than pay, other perks, or the workplace environment.

The manager alone cannot meet the multifaceted goals of the unit. To maintain fiscal responsibility and yet provide high-quality patient care, it is necessary to have a multidisciplinary team that works together in a collaborative fashion. Maintaining a trained team is one of the biggest challenges today. Accordingly, recruitment and retention efforts are crucial.

Recruiting the appropriate staff is essential. Due to the diversity of technical, interpersonal, and critical thinking skills required in a pediatric dialysis program, a candidate with prior pediatric, critical care or dialysis experience is helpful. The necessary skills and behaviors required to perform the job should be defined prior to or during the interview process. Besides experience, it is important that the new hire demonstrate traits compatible with the facility culture. If not present, dissatisfaction quickly occurs resulting in a downward spiral and employee discord. Behavioral questions should be used to help define attributes of the candidate. Some facilities also incorporate personality testing to determine if the candidate's attributes are complimentary to the existing personnel. Advocating for your facility and describing why it is the best place to work is one of the most effective recruiting tools. Entice candidates with your performance records such as patient outcomes, research activities or other factors that favorably describe your workplace. Involving a variety of staff in the interviewing process fosters a team environment and will provide a variety of input. And although money is not the key factor, you must be at least competitive with salaries and benefits when offering a new position if recruiting efforts are to be successful.

Nursing shortages and staff turnover are major issues in health care today. To maintain high standards of patient care with increasing financial limitations, staff retention is a critical issue. Many studies have been conducted to identify key factors that influence retention. One important factor is orientation and career development. Staff members want to be successful in their jobs and want growth opportunities to be available. This begins with a detailed orientation program. Management must assure time and staffing is adequate for appropriate orientation and training of newly hired staff. A willing preceptor who is knowledgeable in established skill competencies should be assigned to each new employee. The goal of the orientation program is a gradual progression

of the new employee's independence with a designated preceptor guiding the progress toward acquisition of knowledge and mastery of skills. Orientation to the specialty can take from 6 weeks to 3 months depending on the new employee's prior experience and learning opportunities. In pediatrics, the occurrence of some clinical situations may be episodic and an employee may not complete the competency checklist by the end of orientation. Thus, simulated clinical experiences may be created to supplement learning. When the infrequently encountered clinical situation does occur, an experienced staff member should assist the novice to enhance skill development and confidence.

An ongoing staff development and education program must be developed based on the learning needs of the staff with a continual reassessment of high-risk procedures [2]. Quality improvement and quality assurance data can identify areas which warrant further review or education. Once a learning need is identified, educational material and periodic skill competencies can be developed to advance clinical knowledge and expertise.

Beyond clinical skills, nurses want customized professional development support. Managers can accommodate this by periodically reviewing educational opportunities and encouraging career advancement. Recognizing certifications, paying professional dues, and offering continuing education classes are additional ways to support career development.

Evidence supports that staff recognition is another key factor influencing staff retention. Employees want more than the established routine recognition programs that exist in hospitals today. They want a 360° recognition program with personalized acknowledgment of their contribution to the success of the facility [9]. It is important to remember that people work for people – not organizations. As human beings, we seek connection with others. People work hardest for bosses who consistently recognize and reward commitment [10–13].

The role between the nurse and physician is crucial. Nurses want collaborative working relationships with physicians. They want physician feedback on protocols, dedicated time to discuss issues, and mutual respect.

Finally, enhancing the quality of work life is the final important ingredient for staff retention. Employees today expect that the work climate will be attractive and accommodate both professional and personal needs [10–12, 14]. They want to be treated fairly and have input regarding job duties and work schedules. Surveys indicate that nursing turnover is twice as high in facilities where there are no scheduling options [15]. Staff wants to have pride in their job and organization. They want to deliver high-quality care and know that their provision of care results in optimal patient outcomes. It is therefore important that the manager procures appropriate resources and support to accomplish this goal.

Staffing the Dialysis Unit

In the United States, individual states have the authority to regulate dialysis clinics, which leads to significant variation in staffing regulations [16]. Some states regulate the ratio of licensed staff, such as nurses, to unlicensed staff, such as technicians. Other states have required patient-to-nurse ratios. Various states have nurse practice acts that limit the practice of patient care technicians in the dialysis clinic. Each nurse must determine what the regulations are in the state in which he or she practices.

As a result of the variation among states – not to mention the added variation in practices outside the United States – there is no recognized standard for how to staff a pediatric dialysis clinic. However, some of the considerations about how to staff a clinic have been studied recently.

Nurse-to-Patient Ratios: Do More Nurses Improve Patient Outcomes?

Although there is a clear association between higher numbers of registered nurses and decreased rates of adverse events and mortality in the hospital setting [17], that association has yet to be shown in the pediatric setting. Dialysis units with higher

numbers of registered nurses do experience decreased rates of skipped dialysis treatments [18], as well as lower rates of hepatitis C seroconversion rates [19]. A recent survey of chronic hemodialysis nurses [20] found that high patient-to-nurse ratios were associated with an increased likelihood of intradialytic hypotension, skipped dialysis treatments, and patient complaints. These studies provide the first empirical evidence that higher numbers of registered nurses can decrease adverse events in the adult dialysis program. It is unknown whether these effects also hold true in the pediatric dialysis program, where nurse-to-patient ratios are typically lower than in the adult program.

Another consideration in staffing is whether the length of the shift has an impact on safety. When determining how to staff the dialysis program, one must consider whether to staff 8-h, 10-h, or 12-h shifts. Many nurses, according to the literature, desire 12-h shifts and report increased job satisfaction, less emotional exhaustion, and more satisfaction with their work schedule. In addition, the units with nurses working 12-h shifts have lower vacancy rates. One of the hazards of working a 12-h shift that does need to be considered is that the shift often stretches longer than 12 h. A landmark study [21] of hospital nurses found that the risk of making an error increased significantly when the shift lasted longer than 12 h, when the nurse worked overtime, or when the nurse had worked more than 40 h in 1 week. However, a recent review [22] of studies examining the effect of shift length on the quality of patient care and on health care provider outcomes (such as job satisfaction and stress), found equivocal results and further research is needed. The implications for dialysis programs could be significant, particularly smaller programs that operate with fewer numbers of nurses.

Another consideration in staffing is managing on-call issues. Most pediatric dialysis programs must provide on-call coverage for home patients and acute treatments. Providing coverage can be challenging when the on-call nurse has already worked a full day in the dialysis unit or is scheduled to work the next day. The question arises: when does it become unsafe for the nurse to continue to provide patient care?

Physicians in residency training and nurses in the perioperative setting face the same issue, and research and guidelines from those disciplines provide dialysis nurses with some recommendations. Physicians in residency training, who work more than 24 h on-call, experience an increased risk of sticking themselves with a sharp object during a procedure, having a motor vehicle crash while driving home, and of making a serious or even fatal medical error [23]. Resident physicians in the United States are currently restricted to working no more than 30 consecutive hours in a shift and their work weeks must average 80–88 h per week [24]. Based on the safety data associated with shifts exceeding 24 h, the Institute of Medicine (IOM) is advocating for resident physician shifts to decrease to 16 h, which has been the practice in New Zealand since 1985. The European Union limits its physician-trainees to 13-h shifts [24].

The Association of Operating Room Nurses has developed guidelines for safe on-call practices [25]. They recommend implementing recuperation periods between regular shifts and call-back shifts, as well as developing a performance improvement system to track whether there is a relationship among errors, adverse events, and number of hours worked during call. They do not provide definitive recommendations about shift length or call length, but rather recommend that each unit should consider patient volume, acuity, and how often call-back occurs when determining on-call guidelines. Finally, they recommend that a sleep room be provided at the facility so that staff has the option to stay on site during call or when called back in order to alleviate sleep deprivation. This factor may be especially important if the staff member is scheduled to work the next day and only has a few hours left to sleep.

In summary, there are no published guidelines about how to most effectively staff a pediatric dialysis program. What little research we have to guide us in the dialysis population comes from the adult population, where the nurse-to-patient ratio is typically much higher. This factor makes it difficult to generalize those findings to the pediatric setting. However, concerns about safety

from shifts that last longer than 12 h and on-call shifts that last longer than 24 h may be valid in the pediatric setting as well, and deserve consideration as we determine how to most effectively staff our programs.

Patient Care Services

Patient care services focuses on meeting the physical and psychosocial needs of the patient. These services include modality selection, development and implementation of care plans, patient and family education, and delivery of patient care. To adequately accomplish these tasks, we must first take into account factors that impact the family when their child has a chronic illness.

Family Adjustment

When parents learn that their child has chronic kidney failure, the coping mechanisms of the family are tested. Some families have had years of interactions with the nephrology team and may have had time to prepare for dialysis. Other families may have received the diagnosis more suddenly and had little time to prepare. Either way, families must adjust to a change in routine and must learn how to care for their child's new medical needs.

As families adjust to having a child with kidney failure, parents experience increased levels of stress, anxiety, and depression [26–29]. Families with children receiving dialysis report an increased disruption in their family life and increased marital stress, but not increased marital breakup [30]. The overall burden of dialysis is stressful and is characterized by themes of uncertainty [31], social isolation [32], and increased vigilance, caretaking, and monitoring [32–34]. In one study [31], mothers of children on peritoneal dialysis described that they were often worried about the possibility of illness or death of their child, and they remained vigilant for complications by checking on their child at night. Fatigue, frustration, and loss of friends were common results that led to increased anxiety and depression among these mothers.

Many nephrologists and nephrology nurses might predict that dialysis modalities that are delivered in the home environment would play a role in how families adjust, since the burden of care giving is significantly higher for these families when compared with in-center modalities. However, studies examining this issue have yielded conflicting results. One study [26] found that parents of children receiving in-center hemodialysis had increased anxiety and depression when compared to parents of children receiving home hemodialysis or continuous ambulatory peritoneal dialysis. However, another study [34] found that home hemodialysis was more stressful for parents than in-center hemodialysis. The relationship between where children receive dialysis and how their families adjust is not fully understood due to the small number of studies in the literature and highlights the need for further investigation [35].

Children themselves also have difficulty adjusting to the burden of kidney disease and dialysis, and studies indicate that there may be both developmental and psychological consequences to the disease process. A study [36] of 16 children who received peritoneal dialysis during the first year of life found that although the children had normal IQ scores, half had behavioral and emotional difficulties. Similar psychological challenges have been identified in another study [37] of adolescent renal transplant recipients. In the long term, young adults who received dialysis as children have difficulty making the transition to adulthood. These dialysis survivors tend to live with their parents longer, have limited social networks, and have difficulty forming relationships with the opposite sex [38].

These studies confirm what we have always known: having a child on dialysis is stressful for both the child and the family. Perhaps the more important question is: does this affect outcomes? One study [27] found that poor adjustment to dialysis was associated with decreased adherence to therapy, which could affect the child's outcome. Another study [39] examined the likelihood of a

patient being referred for transplant by a nephrologist by creating scenarios of children and families with varying characteristics. In this study, the families who were less compliant with therapy were less likely to be referred for transplant. Therefore, there may be relationships among adjustment, adherence, and transplant referral. By paying attention to how families are adjusting to the burden of dialysis, we may in turn be able to ultimately improve the outcomes of these children.

Modality Selection

All dialysis modalities should be reviewed with the patient and family before the patient needs to start dialysis. If this is not possible, modality choices should be reviewed as soon as the patient is medically stable. Specific criteria are necessary if the patient/family is interested in a home modality. The home care provider must be physically able to perform dialysis-related tasks, possess cognitive and psychomotor skills to manage all aspects of the treatment, and be emotionally stable [40–44]. A partner for the home care provider is desirable but may not be necessary depending on the family situation. If a home partner is not available, an emergency backup plan needs to be established in the event of absence or illness of the primary caregiver.

An assessment of the home environment should be performed prior to the initiation of training. A home visit is utilized to assess the general cleanliness of the home, the availability of appropriate electrical access, the water source, telephone accessibility, and the presence of space for storage of supplies [45]. The dialysis team should problem solve with the family to make the necessary environmental changes as needed before home training begins. Burn-out has often been described as one of the biggest pitfalls in home therapy. Therefore, the patient and family must understand and feel assured that they can stop home treatments at any time and the medical team will support their decision. This can be for a short term if respite is needed, or on a continual long-term basis, understanding that a modality change may, in turn, be necessary.

Patient Care Plans

Care plans are developed to promote the maintenance of or improvement in the patient's physical condition, growth, developmentally appropriate activities, and appropriate coping skills for the psychosocial adjustment to chronic illness [5]. Services provided are a continuum of care that requires periodic review, evaluation, and adjustment to meet the needs of the patient.

Considerable improvement in patient outcomes, in both adult and pediatric chronic disease patients, occurs when patients are encouraged to participate in their own care [46]. This not only improves medical outcomes, but encourages independence and builds self-esteem. A care model or plan that will promote these goals should be utilized. Dorthea Orem introduced self-care as a model of nursing practice which is based on key success factors. Adaptations of this model are valid for ESRD programs and should be incorporated into the patient's care or transition plan. These self-care goals promote [46, 47]:

- Maintenance of the pre-ESRD level of involvement in daily activities
- Progression in developmentally appropriate activities
- Increasing involvement in self-care activities

While team input is necessary to develop multidisciplinary care plans, it is important to have someone responsible for the coordination of services. This task has been and continues to be the responsibility of the registered nurse. One nurse is usually assigned responsibility for a designated group of patients. While many facilities refer to the tasks associated with this as primary nursing, today the job description more closely aligns itself with a modified version of case management. This model maintains that one nurse is directly responsible for the ongoing coordination of care for a specific patient and family. Continuity of care and services is accomplished and maintained through this approach. Common duties of

Table 4.3 Responsibilities/duties of the primary nurse or care manager

Utilize the nursing process to assess, plan, implement, and evaluate the patient's care
Collaborate with team, patient, and family to develop care plans
Provide support, and follow-up care through phone contacts and clinic visits
Coordinate other health-related issues: i.e., dental visits, immunizations, etc.
Promote age-appropriate activities and other habilitation goals
Provide appropriate patient education
Promote school attendance and make school visits as necessary
Support home therapy and make home visits as necessary
Act as an advocate for patient and family
Promotes self-care

the primary nurse or case manager are included in Table 4.3.

Patient/Family Education

There are many considerations involved in establishing a pediatric dialysis training and education program. Teaching and educating families is a basic responsibility of pediatric health care providers [48]. When dealing with a chronic illness, education becomes an ongoing process of assessing, planning, teaching, and evaluation. The dialysis team is responsible for the initial and ongoing education and training needs of the patient and family. Establishing a thorough and consistent education/training program is critical [48–50]. Considering health literacy, developing the training materials, and creating a teaching plan are all necessary components for patient education.

Health Literacy and Patient Education Materials

When developing or evaluating the home training and patient education materials (PEMs), the clinic staff must consider the readability of those materials. Unfortunately, the average adult in the United States reads at the eighth-grade level [51], and most PEMs are written at the high school or even college reading level [52]. Since a significant number of people – perhaps up to 40% [51] – read below the fifth-grade level, PEMs should be written at the fifth- to sixth-grade level [52]. It is a waste of valuable nursing time to create materials that are, in essence, unreadable. Therefore, simple tools exist to help determine the grade level that the PEMs are written on. These tools are formulas that primarily take into account sentence length and word length, since longer words and sentences are more difficult for people with poor reading skills to read and understand. Ideally, this process should occur during the development of the education materials but it can be done retrospectively or during revisions. Table 4.4 explains the process for determining the readability of PEMs in electronic and non-electronic formats.

As much as possible, simplify the reading levels. Even adults who read well prefer materials that are easy to read and understand. When designing or rewriting PEMs, you must start by focusing on the actual words and sentence structure. Strive to make the words short (less than three syllables when possible) and easy to understand. Sometimes, a long, dialysis-specific word such as "effluent" may need two shorter words such as "drain fluid" to adequately explain its meaning [52]. Use a consistent word throughout the document, such as "pills," to mean medications or medicines. Define new words. Use the thesaurus feature in your word processor to suggest simpler words as well. Keep sentences less than 10–15 words long, as longer sentences are more difficult to read and understand. Commas and semicolons serve as natural places to divide up long sentences. Finally, write in the active voice rather than the passive voice. We tend to speak in the active voice but write in the passive voice; the active voice is easier to understand. An example of writing in the active voice is to say, "Take your binders with food each time you eat" rather than "your binders should be taken with food each time you eat."

Once the words and sentence structure are written at the fifth- to sixth-grade level, it is time to pay attention to the overall design of the PEMs. The goal is to create something that is visually appealing, uncluttered, and easy to follow.

Table 4.4 Determining readability of patient education materials

If patient education material is in electronic format	If patient education material is not in electronic format
Nearly all word processing programs will display readability statistics	Use the SMOG formula [53]
Readability statistics can often be found at the end of the spelling and grammar check	Pick ten sentences in a row at the beginning, middle, and end of the document (a total of 30 sentences)
Readability statistics change as you make changes in your document	Count every word in the sentences that has three or more syllables. Words that repeat count each time they appear. Proper nouns and hyphenated words of more than three syllables count also. Abbreviations are counted as the whole word they represent
Instructions can be found by searching for "readability" in the Help menu	Determine the square root of the total number of words with three or more syllables
	Add three to the square root. This is the grade level of the document. *Example*: Your 30 sentences have 44 words with three or more syllables. The square root of 44 is 6.6. Add 3 to 6.6 to get 9.6, which is the grade level of the document

A well-designed PEM will help the reader follow along and pick out the most important points. Highlight the most important things you want the reader to remember with bold face, underlining, or italics [52]. Set them off in boxes, or have the reader fill in the information with a "fill in the blank" style, since people tend to remember facts better when they write the information. It is best to use bulleted or numbered lists for procedures and a limited number of fonts, as too many font styles can be distracting or even difficult to read. Make sure that the font size is at least 14-point in order to ensure that it is large enough to be readable by those with poor vision. Be sure to repeat critical information more than once so it is clear that the information is important. Leave a lot of white space on the page and finally, use graphics and pictures to explain difficult concepts and to help illustrate procedures.

Health Literacy, which is defined as the ability to obtain, process, and understand health information, has become an area of significant interest since the IOM released their report on the health literacy status in the United States in 2004. This report noted that 90 million Americans have difficulty understanding and acting on health information, and a growing body of research has demonstrated that low levels of literacy are associated with worse outcomes in patients with chronic diseases. Unfortunately, there has been little research in the adult CKD population and no published research in the pediatric CKD population in this arena [54]. To date, a review of the research [54] of four published studies reveals a mix of literacy levels among the adult dialysis and transplant population. Once we fully understand the literacy levels of our population, both in the adult and pediatric world, the next step will be to determine whether there is a relationship between health literacy and short- or long-term outcomes.

Development of Training Materials

Patient and family training materials are an essential component of any dialysis program. These materials range from brief "hot topics" to detailed training manuals for home families. Care must be taken to assure that materials are developed for the in-center patients as well as the home patient. To help assure consistency of education, specific information related to key issues regarding the management of patient care must be addressed. Examples of topics commonly addressed include:

- Normal kidney function
- Complications of ESRD
- Treatment modalities
- Complications of treatment
- Diet and nutrition
- Fluid balance and control
- Medications
- Laboratory tests and values
- Infection control
- Dialysis catheter and exit-site care

A method of evaluating what the patient has learned is essential [55]. Quizzes can be developed to test the learner's knowledge. Competencies should be developed to evaluate the learner's ability to perform procedures. The quizzes and skill competencies not only give the teacher information about topics needing further emphasis, but also provide the family with immediate feedback and reinforcement of information.

Regardless of the therapy or population being taught, the development of educational materials requires the participation of all the members of the multidisciplinary team. The team should also be utilized to review and update education materials as needed.

Development of a Teaching Plan

Whether teaching a home dialysis family or a patient dialyzing in the facility, an individualized teaching plan should be developed by the nurse responsible for dialysis training. A teaching plan consists of an outline of the content to be taught, measurable behavioral objectives, learning activities, and teaching methods. The individual nurse chooses the specific learning activities and teaching methods to use. Learning activities include reading, hands-on use of equipment, demonstration and return demonstration of procedures, viewing different forms of media, listening to audio tapes, and role playing exercise. Teaching strategies may include lecture, discussion, demonstration, and learning labs [41].

Learning Needs Assessment

In order to develop a teaching plan, a careful assessment of the individuals who are training must first be performed. The family's readiness and ability to learn is examined. Language skills, previous experience and knowledge, coping mechanisms, religions, and cultural beliefs all impact each family member's ability to learn. Barriers to learning such as learning impairments (dyslexia, Attention Deficit Disorder), illiteracy, physical impairments (visual, auditory, speech), illness, and stressors must be considered when developing an individualized teaching plan [41, 48, 49, 55]. These barriers will influence the methods used to teach. It is desirable to provide some education to each member of the family. Even young siblings can benefit from brief education activities.

Although there are many theories, it is not known exactly how people learn. We do know, however, that people learn in various ways. Three basic styles of learning are visual, auditory, and kinesthetic. Once a learner's style is determined, appropriate teaching methods can be incorporated into an individualized teaching plan (Table 4.5) [48, 49].

When teaching a group of people, it is desirable to use a variety of teaching tools which cater to all three learning styles.

Table 4.5 Styles of learning

Learning style	Characteristics of the learner	Supportive learning methods used by the teacher or learner
Visual	Talks fast Talks in half sentences Talks with hands Needs descriptive words Looks at you with blank stare	Writes key words Underlines or highlights key points Draws pictures of words Draws diagrams Learner takes notes
Auditory	Speaks slower Has a full voice Wants all the facts	Speaks just loud enough to be heard Discusses with others Makes "sounds like" associations Makes rhymes
Kinesthetic	Cannot be rushed Touchers/feelers	Behavior modeling Hands on involvement

The Nurse as Teacher

Being able to teach others effectively is a skill, and many nurses lack formal training in how to teach [56]. Thus, it is critical for nurses who teach children and families about ESRD and dialysis modalities to have a basic knowledge of teaching methods in order to be able to teach effectively and to be able to evaluate whether the child and family understand the information that has been taught.

Nurses can be most successful as teachers when clear objectives are used as a guideline for the content being taught [56]. If not already present in the teaching materials, the nurse should ask what the patient should *know* or be able to *do* at the conclusion of the teaching. This information is then used to write specific objectives. For example, if a nurse was teaching a family about the signs of peritonitis, an objective for that content might be: "List three ways you would know if your child has peritonitis." Notice that objectives are limited to one concept and are written in a language that people without medical training can understand. The next objective might read: "Describe what you should do if you think your child has peritonitis." This approach accomplishes two things. First, it keeps the nurse who is doing the teaching on track and ensures that the critical content (the "need to know" rather than the "nice to know") is covered. Second, it allows the nurse to evaluate whether the family understands the information that is presented.

Many nurses approach teaching on an individual or small-group basis. In this venue, teaching by discussion rather than lecture is more effective. By asking questions of the family, the nurse has a good idea of their comprehension of the material presented. In addition, this approach makes the session active rather than passive, which allows for more effective learning.

There are several methods to ask questions in a way that meets the needs of the learner as well as the teacher [57]. Only ask one question at a time, and allow at least 10 s for the learner to respond to the question. Although 10 s seems like a long time, many learners need that much time to process the question and formulate an answer. Avoid saying, "Any questions?", as this approach usually does not prompt the learner to ask questions. Instead, tell the person or group that you expect them to have questions. And you can reinforce this message by making statements such as: "There were a lot of steps in that procedure. I'm sure you have some questions about what I demonstrated." Asking the learner to choose between a few possibilities can also help the nurse assess knowledge. For example, a question about one sign of peritonitis might be, "If your child has peritonitis, would the effluent be clear or cloudy?" Although this sort of question does not invite discussion, the family's answer quickly lets the nurse know if they understand the concept and whether additional teaching is needed. Questions can also be used to help families apply the information that has been presented. For example, after discussing how to assess their child for signs of proper fluid balance, the nurse could ask, "What would a weight gain of 2 lb and a blood pressure of 130/90 mmHg tell you about your child's fluid balance?" This question mimics the data that the parents would have at home and allows the nurse to see whether the family can determine that the child is hypertensive and fluid overloaded.

Additional methods have proven beneficial when teaching children and families. Trivia games have been used successfully when teaching peritoneal dialysis to adults [58]. Patients believed that the games were a fun, active way to learn and the educator found that the game reinforced content covered in the initial training sessions. Hands-on demonstration is an extremely important method for any skill-based content. The nurse should demonstrate the correct order of steps and avoid demonstrating incorrect techniques to the family. Many families also benefit from visual aids that show them the correct order of steps and a picture of someone performing that step of the procedure.

After teaching a concept, the nurse should evaluate whether the family understands the content and can apply the information. Some units prefer to have a written test to document a score. However, a high score on a test does not guarantee that a family can use and apply the information they were taught. It is also very difficult to

Table 4.6 Learning principles of children

Child learning principle	How to apply the principle
Need to know rules and limits	Children have to be told, sometimes shown how, and then told again, especially in new situations. The key is patience
Need for consistency	Staff members must work together to provide consistency in what is taught. Inconsistency can make the child feel confused and insecure or can encourage manipulative behaviors
Need for self-esteem	Belittling or shaming a child is a poor way to discourage a behavior and should be avoided. More effective is to show approval or encouragement of what the child is demonstrating or verbalizing *correctly*. Refrain from labeling a child as a slow learner
Need to have choices	The child needs to feel that he has some control over the learning situation. Give the child a choice when you can, such as when or where the teaching should occur
Need for play	Play is a child's work. By using medical play, the child will develop needed skills for his care

write valid test questions unless the nurse has had specific training in measurement and evaluation techniques. Thus, another evaluation method to use is a checklist that is derived from the teaching objectives. The evaluation of whether a family understands these objectives can either occur at the end of each training session or at the end of the entire training and involves the nurse talking with the family to ensure that they met the objectives. As objectives are met, they are documented and this checklist can then be placed in the patient's chart as evidence of successful training.

When teaching content that involves skills, it is important for the nurse to observe that the family can perform the skills correctly. These observations can also be documented on the evaluation checklist. Ideally, it is also helpful to try to simulate how the family will use the skill in the home environment. For example, after all the training objectives have been met by a family who is learning to perform peritoneal dialysis at home, the nurse could ask the family to set up the peritoneal dialysis machine and connect the child independently without the nurse in the room. Although the nurse is still available for questions, the family will perform the setup without assistance or observation, which simulates what will take place at home. If they are able to successfully complete this task at the end of training, the family feels confident that they can accomplish the same task at home without the nurse's presence. At the same time, the nurse feels confident that the family understands and can apply the information that has been taught during the training. This form of evaluation is very meaningful and provides more information than a score on a written exam.

Teaching Considerations in Children

When teaching children, the level of development must be evaluated. It is not uncommon for a chronically ill child to regress. This regression may be exacerbated by an acute illness or hospitalization. The teaching style and content should be based on the developmental level rather than the chronologic age of the child. In each developmental stage, there are conflicts which cause additional stress to the child. In order for optimal learning to take place, these stressors need to be minimized. Tables 4.6 and 4.7 provide methods to maximize the child's learning potential [12, 13, 48, 49, 59, 60].

Teaching Considerations in Adults

The adult learner may be under a significant amount of stress and feel overwhelmed with the amount of information he/she must learn in order to provide care for their child. All education and training sessions should be done in a relaxed and open setting where they can freely express their feelings. While it is necessary to convey information, it is also important to devote time to develop a positive relationship between the nurse and family. Table 4.8 outlines principles which enhance adult learning [48, 49, 61].

Ongoing Education

The education and training needs of the patient and family continue even after the initial training

Table 4.7 Developmental characteristics seen in dealing with children

Infancy/Toddler (0–30 months)
Stressors to child
Separation from parent
Fear of certain strangers (doctors, nurses, etc.), large objects or machines (scans, x-rays), and change of environment (hospital, clinic)
Loss of control of their environment
Fear of injury
Minimization of stressors
Minimize number of caregivers
Actively involve child in treatment, when possible
Minimize intrusive procedures; do not involve parents as participants in intrusive procedures; rather, enable their presence to comfort the child
Teaching tips
Involve parent in noninvasive cares
Provide choices in age-appropriate activities
Prepare child for procedures, through therapeutic plan and familiarity with medical equipment
Provide age-appropriate activities while waiting
Preschool (30 months–5 years)
Stressors to child
Separation from parents or caregivers
Fear of injury and death
Minimization of stressors
Enable parent to remain with child to provide emotional support
Ask questions of the preschooler and model honest communication
Teach planned coping strategies
Teaching tips
Encourage parental involvement in noninvasive care
Provide accurate preparatory information
Offer psychological preparation prior to and following procedures
Provide age-appropriate activities and play
School age (6–12 years)
Stressors to child
Separation from parent
Fear of staying alone, injury, or death
Forced in a dependent role in having their needs met and the anxiety of body control (i.e., catheter instead of voiding)
Minimization of stressors
Ensure preparation for and involvement in procedures
Involve patient in care
Help children recognize aspects of their effective coping
Teaching tips
Encourage choices among options if possible (i.e., IV in right or left hand)
Teach coping strategies
Provide age-appropriate activities
Adolescence
Stressors to child
Fear of being different from their peers and not fitting in
Fear of death
General lack of trust of anyone other than peer group
Minimization of stressors
Communicate honestly
Involve patient in care and decisions
Address long-term issues in follow-up
Teaching tips
Discuss potential psychological changes and physical responses
Provide opportunity for follow-up discussion and guidance as needed

Table 4.8 Learning principles of adults

Learning is a self-activity
Learning requires active participation by the learner. Learners will learn faster and retain more when they are actively involved in learning experiences
Learning is an interactive process
Hands-on learning experiences will maximize the amount of learning retained
Learning is unique to the learner
Learners are influenced by their past experiences, as well as by their physical environment. Provide for variable interests, opinions, learning styles, and pace of instruction
Learning is influenced by the motivation of learners
Learning is more readily acquired and retained when learners have a strong and sustained desire to learn. Motivation for learning is enhanced when learners can participate in identifying their own needs and planning to meet those needs
Learning is influenced by the readiness of the learner
Learners need to prepare for learning both physically and psychologically
Learning proceeds best when it is organized and clearly communicated
Select appropriate principles (easy to hard, known to unknown, first to last step). Have teaching aids ready when they are needed
Learning is social
Learning is a shared responsibility of teachers and learners. Enhance the social climate for learning by getting to know learners individually. This can be done by: engaging in informal discussions, communicating effectively, and being available as a guide and support
Learning is influenced by the learning environment
The learning environment is both psychological and physical. Provide a comfortable, relaxed, nonjudgmental atmosphere for learning
Learning is facilitated by immediate feedback
Timely rewarding of desired behavior tends to ensure that the behavior will recur. Be generous in dispensing positive feedback. Any negative feedback must be given in a timely, constructive, and sensitive manner
Learning is integrated with knowledge
Learners vary in the speed and effectiveness with which they integrate new learning with old learning. Explaining relationships between old and new concepts will assist learners in bridging these concepts

program has been successfully completed. Over time, breaks in technique or bad habits may develop. In addition, some skills not performed frequently may be forgotten. A clinic or home visit is a good opportunity to review or watch the home care provider demonstrate dialysis-related skills. Skills should be reviewed annually or more often if a problem exists. As the patient matures, they should take a more active role in their care. Special training sessions may be warranted to teach the patient a skill, or convey detailed information that they were not ready to receive during the initial training period. Education and training of the patient and family is a continual process of assessment, planning, teaching, and evaluation.

Care Implementation

Expectations regarding the roles of staff and patients, in relationship to care management, should be clearly outlined and discussed when the patient starts dialysis. Patients receiving treatments in the unit are seen frequently, and so it is easy for staff to assess their needs and provide care. This is more difficult in the home setting where we must rely on patient or family assessments and information. Phone contacts are commonly used to share information and problem-solve situations. However, other means of communicating, such as e-mailing or phone texting, are effective. Contact with the family should occur at least every 2 weeks, and more often if problems occur.

At routine intervals, the patient/family need to be seen in the clinic so the professional staff can assess their current medical status. During this visit, the patient and family meet individually with members of the multidisciplinary team. In this setting, the patient is assessed, medications, diet, laboratory tests and home records are reviewed, and any problems or concerns are addressed. This is also a time when reeducation can occur and transition goals can be updated.

It is important for the multidisciplinary team to meet routinely to review patient data and assure the delivery of consistent care [50, 62]. This care conference allows the team to candidly discuss the patient's health status and update the plan of care. In addition to this, the multidisciplinary team must meet and conduct an in-depth review with the patient and family at least annually. This family conference allows everyone to review the patient's status for the past year and involves the patient and family in establishing care goals. Additional family conferences may be scheduled anytime the family or medical team feels it is necessary.

Meeting with the patient and family outside of the hospital setting can be advantageous. A home visit provides an opportunity for the patient and family to speak in a more relaxed and familiar setting. Other activities such as camp, support groups, and holiday parties take place outside the clinic and provide a valuable opportunity for patients and families to socialize and share common experience and concerns. These also provide an opportunity for both the patients/families and staff to interact with each other in a venue outside of the medical setting.

Habilitation

Promoting normalcy and age-appropriate activities should be incorporated in all health care activities in pediatrics. School attendance and participation in activities is normal for children. In order to support the philosophy of habilitation, the multidisciplinary team must work with the school and family to assure that the patient can participate in as many school activities as possible. Teachers, teacher aides, or volunteers should be utilized to help hemodialysis patients with homework during their treatments. All hemodialysis schedules should be as flexible as possible to minimize time missed from school or school activities. The school teachers, principal, and school nurse need to be aware of any physical limitations and the need for excused absences for clinic visits. For some patients, it is beneficial for hospital staff to make a school visit to speak to the class about dialysis and kidney failure. Young school-aged children are especially receptive to this idea. Absences from school can become a problem. The child can quickly learn that if he voices a physical complaint, he may be allowed to stay home from school. If absences become a repeated problem, the medical team can help evaluate the validity of the situation and work with the family to develop a plan to increase school attendance.

Transition

Transition from adolescence to adulthood is a challenging yet important developmental progression for all children. Patients with CKD must deal with not only the challenges of this transition time, but are also forced to handle additional challenges as we prepare to move them from a health care setting that they are familiar with to a very different adult health care system. As mentioned earlier, chronic illness during childhood and adolescence can adversely affect normal maturation. Missed school and extracurricular activities, over-protection from parents, frequent visits to dialysis units or hospitals, and dependency on dialysis equipment and health professionals all compound to have a negative impact on our patients. Recent quality-of-life studies indicate that children on dialysis have lower self-esteem, and an increased incidence of depression, behavior disturbances, dependency on caregivers, poor school performance, lack of higher education or vocational training, cognitive delays, separation anxiety disorders, and poor social adjustments and peer relationships [63]. With this in mind, it is crucial that pediatric dialysis facilities have a detailed plan for transitioning their patients to an adult facility. A variety of issues should be addressed in such a plan (Table 4.9). An extensive discussion of transition is in Chap. 35.

Table 4.9 Transition topics for patient education

Patient-specific medical condition(s)
Medications including significance, doses
Laboratory tests – significance and interpretation
Dietary restrictions
Sexual health and high-risk behaviors
Educational/vocational plans
Medical complications – anemia, bone disease, hypertension, etc.
Maintaining appropriate health coverage – insurance
Ownership of health care – self-care

Quality Improvement

All facilities must develop, implement, and maintain a data-driven continuous quality improvement (CQI) program. The goal of a CQI program is to continually improve both patient outcomes and system efficiency. This is accomplished by reviewing certain aspects of the care we provide or evaluating the services that we provide. There are numerous things that can be monitored. Treatment adequacy, infections, access failures, and morbidity and mortality rates are just a few things that can be monitored in dialysis CQI programs. In the United States, there are also mandated regulatory requirements that must be monitored. Patient/family complaints and satisfaction should also be a part of your CQI plan. Characteristics or attributes of "good patient care" are viewed differently by professional staff and patients/families. Reviewing patient surveys can offer insight regarding the services you provide.

Benchmarking is another way to review the status of your program and can be a valuable tool for your CQI program. Benchmarking databases provide you with the ability to compare your outcomes to those in other centers while also providing consensus information which can help you establish appropriate target ranges for the outcomes you are monitoring. The International Pediatric Peritoneal Dialysis Network (IPPN) allows participants to view benchmark data for peritoneal dialysis care, and the North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS) offers pediatric benchmarking of outcome data for all stages of CKD, transplant, and dialysis. These two databases house a wealth of information that can assist a program in the identification of areas in need of improvement or areas of high achievement.

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