2008

GUIDE TO CARE AGREEMENTS

An Effective Way to Address Challenging Situations

For the Renal Community

Prepared and provided for you by

Heartland Kidney Network

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The Heartland Kidney Network often works with the renal community to address challenging patient and provider situations. More treatment providers are using "behavioral contracts," referred to in this document as care agreements, to help address and manage challenging situations and patient behaviors.

The Heartland Kidney Network believes care agreements, if used correctly, can be beneficial for both the patient and the provider. Some of the potential benefits are:

Benefits to Provider	Benefits to Patient
▪ Improved communication	▪ Improved communication
▪ Defined plan to address particular situations, events, or behaviors	▪ Defined plan to address particular situations, events, or behaviors
▪ More consistent care by the treatment team	▪ More consistent care by the treatment team
▪ Opportunity to review expectations with patient	▪ Opportunity to review expectations with staff
▪ De-escalation of the situation	▪ De-escalation of the situation
▪ Improved documentation of the problem and any attempts by the provider to resolve the problem	▪ Opportunity to have care concerns and any request of staff documented
▪ Increased team communication	▪ Increased motivation to change
▪ Process of creating the care agreement can assist the team in formulating thoughts and building consensus	▪ Improved health outcomes
	▪ Decreased stress
▪ Helps managers support the treatment team	▪ Decreased conflict with members of the treatment team
▪ Communicates the seriousness of the situation to the patient	

There are, however, some situations in which care agreements either are not appropriate or are not necessary. In fact, an inappropriate or poorly thought-out care agreement could easily escalate and complicate a situation.

The Network has created the following document in an attempt to assist providers in determining when a care agreement may be helpful. The document also provides information and tips on how to structure an effective care agreement.

Unsure about whether or not the situation would improve with a care agreement? Consider these questions before making a decision…

Is the behavior changeable?

Consider any precipitating factors that make a change in the behavior unreasonable or unlikely–such as mental illness, dementia, or financial limitations. If psychosocial factors prevent the patient from changing behaviors, you may find yourself creating an agreement that only complicates the situation and has no chance of being successful.

> ***EXAMPLE:*** *Johnny Patient has mild mental retardation and cannot understand the terms or consequences of an agreement to control his verbal outbursts during treatment.*

> ***EXAMPLE****: Jenny Patient suffers from mental illness, is homeless, and is often late to dialysis. He tries hard to get to dialysis on time but just sometimes cannot make it because of the bus schedules and his inability to organize his life.*

Is the behavior measurable and specific?

Just like when you go on a diet and you can't tell whether or not it was successful unless you weigh yourself, you also can't tell whether or not a care agreement was successful unless you have something to monitor and measure. You need to be able to clearly identify the problem behavior and the specific goal of the agreement in order for the patient to have a chance of changing.

> ***EXAMPLE:*** *"Jenny Patient is always disagreeable." This statement does not tell the patient what specifically needs to change. How are they disagreeable? Do you have to be agreeable to be on dialysis? How do you monitor or measure disagreeable?*

> ***EXAMPLE:*** *"Johnny Patient is missing too many treatments." How many treatments are too many? Do you have a number to present him with? Do you have documentation that shows his missed treatments?*

Is the behavior persistent?

There are sometimes circumstances that lead to an unusual situation or behavior from a patient, yet it is clear that the behavior is not persistent. In these cases, a care agreement is probably not necessary since there is no need for change to occur over time.

> ***EXAMPLE****: Johnny Patient is normally a very passive person, but he recently became very angry and yelled profanities while sitting in the lobby. In a discussion with the Social Worker after the incident, it was discovered that he was under a great deal of stress due to a recent death in his family. Instead of using a care agreement, he was educated about the inappropriateness of his behavior and was referred for counseling.*

If not a Care Agreement, Then What?

If you decide a care agreement is not necessary, it is still important to consider how the problem will be addressed. Here are a few suggestions.

Address the problem directly

Many problems can be resolved merely by bringing attention to them. This is especially true when a patient is unaware that the behavior is a problem - pointing it out to the patient may be the only solution needed.

> ***EXAMPLE:*** *Jenny Patient disagreed with the weight on the scale during her last treatment and became very loud and argumentative. In a meeting with her, she was told that her behavior was alarming and intimidating to other patients. Jenny Patient did not realize that others saw her actions as threatening.*

Hold a care meeting

Scheduling a meeting between the patient and care team often helps address problems. Care meetings help improve communication and empathy for all parties involved in the situation. If conducted in a supportive and caring manner, patients sense how their behavior is negatively affecting the care team and dialysis unit.

> ***EXAMPLE:*** *The care team meets with Mr. Patient to discuss ongoing problems with the patient yelling at staff. During the meeting, Mr. Patient shares that he is not sleeping and may be losing his job. The care team shares how his yelling has caused some staff to be in tears and other patients to worry about their safety.*

Write a letter

After discussing a problem, you may want to follow-up the conversation with a letter thanking the patient for listening and reviewing the highlights of the conversation.

> ***EXAMPLE:*** *Mr. Patient, I wanted to thank you for taking the time yesterday to discuss our concerns. It was clear to me in the conversation that you have a very good understanding of your dialysis and renal failure. I would like to take a moment to review what we agreed would be the plan to address your concerns.*

Educate the patients

If an issue appears to affect more than just one patient, consider providing education to all patients through memos, meetings, bulletin boards, etc. This may help to resolve the current problem while at the same time helping to prevent other problems in the future.

> ***EXAMPLE****: Jenny Patient became disruptive when told that the unit would be implementing a policy of no eating or drinking on the machine. After the incident, all patients were educated more about the reasons for the new policy and about their options.*

Educate the staff

Patients may not be the only ones who need education in a dialysis unit when there is a problem or a concern. Having problematic behaviors in a dialysis facility can be challenging for all staff, and dealing with them is an ongoing learning process. Determine whether or not staff would benefit from additional training and/or education with regard to a specific problem.

***EXAMPLE**: For a number of months, Mr. Johnny Patient has been making jokes of a sexual nature with a staff member. The staff member has tried to ignore the jokes. Mr. Patient then makes a comment about her breasts. The staff member gets very angry with the patient and refuses to work with the patient again. The patient gets upset and calls the staff member an insulting name. The unit manager works to resolve the problem between the staff member and patient, and also decides to hold an in-service on how to handle inappropriate comments from patients.*

Review policies and procedures

Patients respond to structure and consistency. Conflict and problem behaviors often occur in treatment settings when the unit does not have clear policies and procedures - or staff is not consistent in following them. In fact, it is often more important how consistently a policy or procedure is followed by staff than what the policy and procedure states. Hold a team meeting to review policies and procedures. Discuss any discomfort in following the policies and procedures.

***EXAMPLE**: The dialysis unit policy is to not put patients on early. Johnny Patient often arrives to dialysis early. For the past few months, several staff has been able to put Johnny Patient on early. Unfortunately today, the technician is running behind and tells Mr. Patient that he will have to wait for his regular on time. Mr. Patient becomes extremely angry with the technician.*

Develop a team plan for dealing with the patient

Some patients will always be more challenging and will require additional teamwork, communication, and planning. For these patients, the team should develop a detailed written plan on how to best manage the patient. It will be important that the members of the team understand the plan and are supportive of it. If the plan alters expectations or unit policies, the patient needs to be informed of those details.

***EXAMPLE:** Mr. Johnny Patient struggles with anxiety problems. When working with Johnny Patient, please do the following: (1) Do not ask him unnecessary questions; (2) Refer all medical questions to the nurse case manage; (3) Care plans will be reviewed with the patient by the unit manager,etc.*

We are developing a Care Agreement… What Now?

Although care agreements can vary greatly among patients and situations, the following are some general guidelines that can be considered once you have decided to try a care agreement.

Make the agreement specific and individualized

The most important thing to keep in mind when developing a care agreement is that each patient and each situation is different. Just as a physician must take into consideration the medical needs of a patient before he/she can prescribe medication, request dialysis treatments, or perform surgery, so too must the dialysis team when considering how to manage patient behaviors.

> ***EXAMPLE:*** *The team met with Mr. Patient to determine how a care agreement could work specifically to help him increase his compliance regarding treatment. The team considered all of his barriers and came up with an agreement that everyone considered fair and appropriate for his situation.*

Get in the game early!

If there is a persistent, problematic behavior that you have noticed with a patient, don't wait for it to escalate into a difficult-to-manage or even dangerous situation. It is important to educate all staff about what to do when a patient is displaying inappropriate, difficult, disruptive, abusive, noncompliant, or unwanted behavior. Addressing the issue early, when the patient and staff are all willing to be flexible, could save you time and energy in the long run.

> ***EXAMPLE:*** *Jenny Patient has been yelling at staff during treatments for the past three weeks, and has become increasingly louder and more aggressive. To prevent further escalation of the situation, the team met with Jenny and an agreement was implemented that gave Jennifer a means to address her concerns with staff, and also provided her with consequences in the event that the behaviors continue.*

Make the agreement measurable and observable

Unless an agreement is measurable, all parties will have difficulty knowing whether progress is made. When writing the contract, it is helpful to think in terms of what results you hope to achieve and how they will be evaluated at the end of the contract period. It is similar to weighing yourself at the end of a diet to see how much progress you've made.

> ***EXAMPLE:***
> *Rather than:* *"Johnny Patient will not be mean to staff."*
>
> *Try this:* *"Johnny Patient will refrain from cursing at staff."*

Make the goal achievable and the expectations reasonable

Remember that the goal of a behavior change is to improve a behavior - not to make a "perfect patient." Get input from the patient on setting goals that are realistic. Keep in mind that smaller steps allow both parties to note success and feel like some progress is being made on larger problems.

> ***EXAMPLE:***
> *Rather than:* *"Johnny Patient will not miss any of his treatments."*

Try this: *"Johnny Patient has been attending only 8 treatments per month. Within the next 2 months, Mr. Patient will attend at least 11 treatments per month." (Mr. Patient expressed that attending all treatments was unrealistic right now due to childcare issues, but he feels he can manage 11.)*

Keep it positive!

Avoid using negative language, medical terminology, and character statements. Care agreements should also not sound like legal contracts.

EXAMPLE:

Rather than: *"Johnny Patient is disrespectful and hateful to staff. You will treat staff with respect and follow their direction at all times."*

Try this: *"In the care conference, you acknowledged getting angry with staff several times during the past month and calling them inappropriate names. We understand that you have some care concerns and reasons to be frustrated. However, you can not raise your voice and call staff names."*

Provide appropriate consequences

In order for a care agreement to be effective, any consequences must be clear, reasonable, and enforceable. The treatment team - including the patient's physician, nursing staff, and administration - must be willing to follow through with the consequences or the care agreement will only complicate the situation. Furthermore, failure to enforce the care agreement will likely have a negative impact on team moral and trust.

EXAMPLE: *"Johnny Patient will refrain from cursing at the staff and patients during treatment. If he curses during treatment, his Nephrologist will be notified and Johnny's treatment will be discontinued for the remainder of the day."*

Use progressive consequences

Most patients will test the care agreement and the resolve of the team at least once. How your staff handles the first test of the agreement will be critical. If possible, it is also best to have progressive consequences to allow the patient some room to test it. Progressive consequences is especially important if a treatment center has not always been good about following up on consequences in the past with the patient.

EXAMPLE: *" If Johnny Patient yells at the staff during his treatment, his treatment will be discontinued for the remainder of the day. If he has a second incident of yelling at the staff, his treatment time will be changed to a morning schedule."*

Attempt to include the patient in the process

Being involved in the goal-setting process will allow a patient to assume responsibility for a goal, and thus motivate him/her to achieve the goal. Consider having a confidential meeting with the medical team and the patient (including a support person, if the patient desires) in which the care agreement can be developed. This will also help to prevent the patient from feeling isolated or "ganged up on," which can lead to his/her disinterest or refusal to participate. However, if a patient refuses to participate in the process, a care agreement can still be implemented.

EXAMPLE: *"Jenny Patient has been late for treatments for the past several months. The team met with her and her husband to discuss the issue and to come up with an agreement that worked for them and the facility."*

Include the staff in the process

A care agreement is an agreement between two parties, so consider ways that the staff can be involved in the patient's process of change. Educate staff about their roles in the process.

> ***EXAMPLE:*** *"Mr. Patient will alert the Tech in a normal tone of voice if he is not feeling well during treatment. The staff will respond to Mr. Patient within 2 minutes and will notify the Nurse if Mr. Patient needs additional assistance."*

Make the agreement time-limited and monitor the patient's progress

All care agreements should have a clear beginning and ending date. This contributes to a patient's sense of accomplishment at the end of the period. Likewise, it is essential that the patient's progress be monitored, whether through meetings, phone calls, correspondence, etc. Gauging a patient's progress throughout the contract period will encourage him/her to stay on course.

> ***EXAMPLE:*** *"Johnny Patient will only be able to change his dialysis schedule 3 times in one calendar month. This care agreement will be reviewed in 3 months. If the patient has followed the plan, the patient care agreement will end."*

Remember to document!

Make sure that all of the team's efforts and the patient's progress are recorded somewhere, and include specific documentation in the patient's record.

Remember to include important information!

When presenting the care agreement, you should (at a minimum) include the following items: (1) a copy of your patient rights and responsibilities document, (2) a copy of your grievance procedure, and (3) the contact information for the Heartland Kidney Network and State Survey Agencies.

A care agreement is not a 30-day notice of termination

A care agreement should not be combined with a 30-day notice of termination. If the problem behavior could lead to termination of service, it is appropriate to indicate so in the care agreement. If the patient fails to follow the terms of the agreement and the behavior falls within the legal and ethical reasons for termination, the patient should then be given a 30-day notice. Refer to the *Decreasing Dialysis Patient-Provider Conflict (DPC) National Task Force Position Statement on Involuntary Discharge.* It is included with this document for your convenience.

Example Structure for a Care Agreement

Date:

To:

From: Unit Manager

Re: **Care Agreement**

Concern:

This section would include the following information:

- *A summary of the concerns, including specific details such as dates, times, frequency, etc.*
- *A review of prior attempts to resolve the issues*
- *A review of unit policies and procedures and patient rights and responsibilities*
- *Health and safety concerns for the patients and others*

Plan of Action:

This section would include the following information:

- *All specific actions to be taken by the patient*
- *All specific actions to be taken by the staff*
- *Any consequences for failing to follow the terms of the care agreement*

This section should be as detailed as possible so that roles and expectations are clear. It should use non-judgmental language. Numbering or bulleting are a good way of structuring this section.

Example:

(1) *You agree to be in your dialysis chair 15 minutes before your scheduled on time.*

(2) *If you are not in your chair 15 minutes before your scheduled time, you may have to wait for staff to complete other assignments or to return from break.*

(3) *Your dialysis off time will not be extended.*

(4) *If you are late more than 4 times a month, you will be moved to the last dialysis shift of the day.*

Effective Date of Agreement:

Review Procedure:

The status of the concerns and this care agreement will be reviewed with you every month. The review will provide everyone an opportunity to provide feedback on the agreement and to review the progress. If in 3 months, you have followed the terms of this agreement, the care agreement will no longer be in place.

By signing below, you acknowledge and understand the patient expectations for dialyzing at this facility and the specific conditions of this agreement.

_____ Date _____
Patient Signature

_____ Date _____
Unit Manager Signature

_____ Date _____
Medical Director Signature

_____ Date _____
Nephrologist Signature

Decreasing Dialysis Patient-Provider Conflict (DPC) National Task Force Position Statement On Involuntary Discharge

Executive Summary

The Task Force [i] believes that there is a substantial need to give providers guidance regarding the Ethical, Legal and Regulatory issues related to the involuntary discharge of ESRD patients by either the nephrologist or a certified dialysis center or facility. Most ESRD patients are covered by the Medicare ESRD Program and as such are entitled to receive a payment subsidy to their ESRD providers by the federal government for the life saving chronic treatments they require. Dialysis facilities become certified for this purpose and accept Medicare funding to provide these treatments and other services to Medicare Beneficiaries.

When conflicts arise related to patient behaviors that are deemed unacceptable by the providers, then questions arise as to the rights and obligations of both the patient and provider in the Medicare entitlement system. This paper sets forth the following positions:

• Medicare beneficiaries with ESRD are entitled to partial government payment to providers for chronic dialysis treatments under the Social Security Act.

• Providers have legal authority to refuse to treat patients who are acting violently or are physically abusive thereby jeopardizing the safety of others.

• The use of contracts to facilitate effective and efficient use of facilities is permissible.

• Although a patient may unilaterally terminate the patient-physician relationship, the physician may terminate the physician-patient relationship only after taking steps necessary to fulfill ethical obligations and to avoid legal abandonment of patients.

• A certified facility cannot provide dialysis without a treating physician and thus must discharge a patient if the treating nephrologist terminates the patient physician relationship, or transfer the patient's care to another treating nephrologist within that facility. However, both the physician and the facility are obligated ethically, legally and by regulation to assist the patient in securing life saving treatment with another facility and/or nephrologist.

• It is unethical for patients to be left without treatment based solely upon nonadherent behaviors that pose a risk only to them i.e., non-adherence to medical advice.

• Groups of providers should not exclude patients from acceptance and treatment from all their facilities or other physicians, except for irreconcilable cases of verified verbal/written/physical abuse, threats or physical harm. These groups should endorse and act on the ethical obligation to transfer patients to others within their group. An important purpose of transfer is to ensure that personality, language or cultural issues particular to an individual patient, professional or facility are not significant causes of the problem behavior of the patient.

Background

In the early years of dialysis, those fortunate enough to have access to the treatment followed closely the recommendations of their providers. However, increases in dialysis patients in recent years and a shift in the demographics of the patient population have changed that pattern. Staffing issues have also contributed to the situation. Once nurses served on the front lines of dialysis care, spending time tending not just to the disease's physical demands but emotional ones as well.

As dialysis has evolved and financial pressures have outpaced facility reimbursement increases, facilities, aiming to streamline operations for financial efficiency, now rely on technicians to do the jobs nurses once performed. Technicians may inadvertently exacerbate the potential for conflict because they have not had the formal education or professional training of licensed caregivers.

Technicians may not be as proficient licensed caregivers in defusing potentially explosive encounters. If situations escalate out of control, dialysis units – faced with monetary and staffing constraints – may find it easier to dismiss problem patients rather than thoroughly assessing and responding to their complex problems. All these factors combine to set the stage for conflict. [ii]

In the years 1999 & 2000 the ESRD Networks (NWs) perceived an increase in the number of contacts and complaints regarding disruptive and abusive patients. The number of involuntary discharges of patients both with and without placement in a new facility increased for various reasons including non-adherence (non-compliance) to treatment regimens. A workgroup organized by the Forum of ESRD Networks, designed a Centers for Medicare & Medicaid Services (CMS) approved national project, with the purpose and goals of beginning to quantify the number of (HD/PD) patients involuntarily discharged, gain an understanding of the reason(s) for the discharges, describe the characteristics of the involuntarily discharged patient population and identify placement outcomes for these involuntarily discharged patients.

Over 70% of ESRD facilities and patients in the US in 2002 were included in the project. Of the 285,982 patients included in the project, 458 (0.2%) were reportedly involuntarily discharged. Treatment non-adherence was the leading reason for discharge nationally at 25.5% (117 patients), followed by verbal threat at 8.5% (39 patients). Other reasons for discharge were lack of payment at 5.2% (35 patients), combinations of verbal abuse, verbal threat and physical threats at 5.2% (24 patients) and verbal abuse at 5% (23 patients).

The Task Force noted that discharged patients are at high risk for morbidity and mortality. Any ESRD patient without access to regular chronic dialysis and the necessary support services is at increased risk. An unknown number of deaths have occurred due to lack of access to dialysis. Although the numbers are thought to be small, these deaths may have been preventable. They evoke disturbing ethical questions, particularly in the case of any discharge for nonadherence (resulting only in a danger to self rather than a danger to others) when the patient has exercised his/her legal and ethical right to consent to or refuse medical treatment.

The Forum of ESRD Networks convened a national consensus conference in October of 2003 to explore dialysis patient provider conflict. Renal stakeholders and CMS participated in the conference during which action options were identified to address these issues. CMS subsequently funded a national project titled Decreasing Dialysis Patient-Provider Conflict (DPC project) to act upon several of the action options, including the need to clarify the rights and obligations of patients and providers in an entitlement system. A national Task Force was formed for this project and a subcommittee activated to examine the legal, ethical and regulatory issues of entitlement and to produce a statement for national consideration.
This statement addresses three levels of behavior:

- Behaviors, physical acts, nonphysical acts or omissions by a patient that result in placing *his/her own health, safety or well being at risk* (frequently referred to as non-adherence to medical advice).

- Behaviors, actions, or inactions by patients and/or family, friends or visitors perceived to put the safe and efficient operations *of the facility at risk* (for example frequent "no-show" for treatment or non-payment, frequently referred to as non-adherence to facility policy and procedures).
- Behaviors, actions or inactions by patients and/or family, friends or visitors that are perceived to place the health, safety or well-being of *others at risk* (commonly referred to improper behaviors that impinge on the rights of others).

Discussion

Ethical & Legal Issues

Physicians cannot be, nor should they be, forced to accept a particular patient into their care. Physicians have no legal or ethical obligation to sustain or maintain a relationship with an uncooperative patient. However, once a relationship has been established between the physician and patient, a legal and ethical obligation exists to continue that relationship until it is formally terminated or until the patient voluntarily withdraws from care. These ethical obligations are not absolute and providers should clearly consider the safety and well being of others when weighing this decision [iii, iv]. If a situation arises where neither party can provide what the other needs, the relationship may be terminated; however, a physician may not abandon his/her patient. The physician must give notice and the patient must have an ample opportunity to secure the presence of other medical attendance [v]. A minimum of 30 days notice has been recognized in case law and good faith assistance of the physician is recommended. In cases when no other nephrologist either practices in the geographic area where the patient is treated or no other nephrologist will accept the patient, the physician has a duty not to abandon his/her patients and should make a concerted effort to work out an acceptable treatment program.

Treatment Issues

Referral to an alternate provider may be impossible due to refusal of other providers to accept the patient or due to a lack of alternate providers in the area. In such cases, aggressive steps are needed to continue treating the patient. These steps include but are not limited to the following:

- Evaluation of the role of metabolic side effects of treatment, endocrinopathies and medications on patient behaviors.
- Focused interventions by each member of the interdisciplinary team including a complete assessment of needs and planned interventions together with referral to a mental health specialist that may result in beneficial changes [vi] or consultation with an Ethics Committee [vii] l
- Isolation of the patient during treatment or moving the patient to another shift
- Psychiatric evaluation as required by facility for continued treatment; in some cases this may involve a court order
- Attendance of family members/significant others during treatment to contain patient behavior; in some cases this may involve a court-order
- Cases that involve physical attack or other violent conduct where others are placed at risk are best handled by referral to the appropriate law-enforcement agency

Providers should thoroughly document inappropriate patient behavior and provider efforts to assist patients achieve more appropriate conduct. If the decision is made to discharge a patient involuntarily, there should be clearly documented evidence that the patient's rights have been protected, that aggressive measures to modify inappropriate conduct have been attempted and been unsuccessful. Finally, as stated by CMS to ESRD Networks a) providers are "required to assist with alternate placement", b) "(placement) is not the responsibility of the Network", c) "whenever possible the patient's nephrologist should be involved in the discharge and transfer planning." Earnest attempts to accomplish an orderly transfer [ix] to another provider must be fully documented.

Protocols should be adopted that make available, where possible, the intra-corporate placement of discharged patients whose behaviors *place themselves at risk* since some behavioral problems may be resolved by the characteristics of a new environment and new treatment team. These protocols should include an alternate provision for placement consultation with providers from different organizations in cases

where transfer within the same corporation is not possible. Prohibition on intra-corporate transfers is inappropriate except in well-documented cases when a patient places *others at physical risk*.

While the use of "Zero-Tolerance" policies is adopted in some settings, these policies are very often inappropriately and inconsistently enforced and open to broad subjective interpretation. The use of Zero Tolerance Policies is supported only for behaviors that place *others at physical risk*. Aggressive measures should be attempted to resolve conflicts involving other inappropriate nonviolent behaviors.

It is the position of this Task Force that terminating the patient/provider relationship on the basis of behaviors that place *only the patient at risk* is unjustified. In the limited instances where the behaviors are so pervasive as to create significant *financial &/or operational risk to the facility*, consideration could be given to employing an approach wherein the "privilege" of a regular outpatient appointment slot is withdrawn after advance notice and informed consent and the patient assigned to dialysis by vacant spots that arise when other patients are hospitalized, absent or dialyzing elsewhere. This approach may be successful in continuing to offer dialysis and provide appropriate support services while allowing regular assignments to adherent patients, and eliminating the financial burden of repetitive "no-show" behavior. In such a treatment plan, if the patient demonstrates compliance with regular treatment, a regular slot can be offered when available and a treatment contract employed. If the patient is in emergent need of dialysis when no spot is available, the patient would be directed to the Emergency Room for acute services, as is routine in ESRD care.

Effects on Outcome Data

Under Congressional mandate, Networks evaluate the quality of care rendered by ESRD providers. This oversight function may lead some providers to regard patients *whose behaviors place themselves at risk* as liabilities to their facility's quality indicator profiles. In other words, nonadherent patients could be viewed as a 'risk to the facility' by worsening the facility's outcome measures. Although current data systems do not allow for case mix adjustment or censoring of patient data with poor outcomes due to nonadherence, it is the position of this Task Force that no negative conclusions should be drawn about practitioner or facility quality of care based upon data for patients who do not cooperate with the prescribed regimen. The Network Medical Review Boards, therefore, in their quality oversight role, should not hold providers responsible for aberrant quality indicators in such cases, since patients cannot and should not forcibly be made to receive dialysis therapy as prescribed, nor comply with other aspects of the treatment program, including diet and medication orders, if they choose otherwise. The Networks should request further information from providers in cases where facility outcomes appear as outliers, allowing facilities the opportunity to justify outcomes that are directly related to the continued care of patients who do not cooperate with the treatment regimen.

Recommendations

1. When discussions regarding discharging a patient arise, the interdisciplinary care team should consider the ethical, legal, and regulatory obligations toward the patient who requires life-sustaining treatment.
2. Treatment should continue without bias or discrimination towards patients whose behaviors place only them at risk.

3. Although current data systems do not allow for case mix adjustment or censoring of patient data with poor outcomes due to non-adherence, it is the position of this Task Force that no negative conclusions should be drawn about practitioner or facility quality of care based upon data for patients who do not cooperate with the prescribed regimen. We recommend that the Network Medical Review Boards and other quality oversight agencies consider the effect of non-adherence on aberrant quality indicators, since patients cannot and should to forcibly be made to receive dialysis therapy as prescribed, nor comply with other aspects of the treatment program, including diet and medication orders, if they choose otherwise. It is recommended that further information be requested from providers in cases where facility outcomes appear as outliers, allowing providers the opportunity to justify outcomes that are directly related to the continued care of patients who do not cooperate with the treatment regimen.

4. All members of the renal health care team should receive training in conflict resolution and develop skills in this area.

5. Each facility should develop a comprehensive, multidisciplinary policy for intensive intervention that recognizes the rights of both patients and staff and includes early consultation with provider support services and the ESRD Network, to resolve conflicts among patients, renal care team professionals, and the facility.

6. Consideration of potential contributing clinical side effects of treatment, endocrinopathies and medications on patient behaviors should be documented.

7. In the rare event a decision is made to terminate the physician/provider- patient relationship for behaviors which put the facility or others at risk, multidisciplinary renal care team good faith attempts at intensive interventions should have occurred over a reasonable period of time prior to the decision. Treatment should be continued until the patient-provider relationship has been legally and appropriately terminated. This includes advance notice and directly contacting other nephrologists and dialysis facilities to obtain alternate care. It is recommended that transfer within provider groups be facilitated if required to ensure continued treatment.

8. In addition to the provision of a list of other nephrologists and dialysis facilities the discharging facility has an ethical responsibility to the patient with a life threatening condition to actively participate in a well documented, good faith effort to obtain dialysis placement to ensure continuity of care. This involves:
    a. Active involvement of the patient's nephrologist
    b. Provision of accurate medical records and information to prospective providers in accordance with HIPAA and/ or the Federal Privacy Act including the reason for discharge
    c. Informing the patient of his/her rights under HIPAA to:
        i. Review records for transfer AND
        ii. Submit a statement in a reasonable time prior to the transfer for inclusion in medical record if not in agreement with the record

    d. Prospective providers have an ethical obligation to earnestly consider accepting patients who have been discharged by other providers. This may require:
        i. A face-to-face meeting with the potential provider, patient and family
        ii. Use of treatment trials and behavior contracts

9. When chronic placement is not obtained, the discharging physician and facility should work with area providers to ensure continued treatment.

The DPC National Task Force adopted this position statement on January 14, 2005.

The following renal stakeholders have endorsed the statement:

- American Association of Kidney Patients
- American Nephrology Nurses Association
- Gambro Healthcare
- National Association of Nephrology Technicians/Technologists
- National Renal Administrators Association

References

I. Decreasing Dialysis Patient Provider Conflict Project National Task Force: Center for Medicare & Medicaid Services representatives-Ida Sarisitis, Gina Clemons, Condict Martak, Brady Augustine, MS, Barry Straub, MD; Richard S. Goldman, MD, Co-Chair; Glenda F. Harbert, RN, CNN, CPHQ, Co-Chair; Karin Anderson-Barrett, BSN, RN, JD (DCI); Elaine Colvin, RN, BSN, MEPD (ANNA); Sandie Guerra Dean, MSW, LICSW (FMC); Cammie Dunnagan (eSource); Brenda Dyson (AAKP); Wendy Funk-Schrag, LMSW, ACSW (CNSW & RCG); Clifford Glynn, CHT (NANT); Kay Hall, BSN, RN, CNN (GHC); Barry Hong, PhD, ABPP (psychologist); Liz Howard, RN, CNN (Davita); Denise Rose, JD; Ann Stivers (NRAA); Mark Meier,MSW, LICSW; Arlene Sukolsky; Lisa Taylor, BSN, RN; Sandra Waring, MSN, CNN, CPHQ (Forum of ESRD Networks); William Winslade, PhD, JD (medical ethicist).

II. Report of the Dialysis Patient-Provider Conflict (DPPC) A Consensus Project with the Participation of the Community of Stakeholders Final Report. 2003.

III. Section 5 (a) (1) of the OSHA Act "Each employer shall furnish to each of his employees employment and a place of employment which are free from recognized hazards that are causing or are likely to cause death or serious physical harm to his employees." OSHA Guidelines for Preventing Workplace Violence for Healthcare and Social Service Workers.

IV. OSHA Safety and Health Program Management Guidelines (Federal Register 54 (16:3904-3916, January 26,1989). OSHA Guidelines for Preventing Workplace Violence for Healthcare and Social Service Workers.

V. American Medical Association Council on Ethical and Judicial Affairs states that a "physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable notice and sufficient opportunity to make alternative arrangements for care".

VI. ESRD Network of TX, Inc. Intensive Intervention With The Non-Complaint Patient Booklet

VII. Renal Physicians Association/ American Society of Nephrology Clinical Practice Guideline Shared Decision Making in the appropriate Initiation and Withdrawal from Dialysis

VIII. Centers for Medicare & Medicaid Services ESRD Network Organization Manual 130.11

IX. Subpart U Conditions for Coverage of Suppliers of ESRD Services 405.2138

In addition to these materials, the Heartland Kidney Network is available to assist facilities in constructing effective care agreements. For more information contact the Network's Patient Services Coordinator at the address or phone number listed below:

Heartland Kidney Network
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Kansas City, MO 64153
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Fax (816) 880-9088
Website: www.heartlandkidney.org

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