THE DECREASING DIALYSIS PATIENT-PROVIDER CONFLICT (DPC) PROJECT

FINAL REPORT

DECREASING
DIALYSIS
PATIENT-
PROVIDER
CONFLICT

JUNE 2005

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BACKGROUND

Conflicts between dialysis patients and those who provide their care is perceived by the ESRD Networks, the Centers for Medicare & Medicaid Services (CMS), and the ESRD provider community to be a growing problem. In 2001, Networks 11 and 14 conducted independent queries of the outpatient dialysis facilities to better understand the issue of involuntarily discharged dialysis patients. In 2002, Network 11 partnered with Network 14 to obtain CMS approval for a national survey of involuntarily discharged patients. This multi-Network survey of Involuntary Discharged patients involved twelve ESRD Networks, and the survey found patient noncompliance to be one of the most common reasons for patient discharge.

In 2003, with the leadership of the Forum of ESRD Networks and the support of an educational grant from ESRD Network 12, the Dialysis Patient-Provider Conflict (DPPC) project was initiated. On October 2-3, 2003, a meeting was convened with **25** stakeholder representatives and **21** observers from **27** organizations involved in the DPPC initiative. At this meeting, the participants described **67** challenges to improving patient-provider conflict and proposed **40** action items for addressing these challenges.

Stakeholders participated in the Dialysis Patient-Provider Conflict (DPPC) Consensus Conference Delphi Survey indicating their commitment to support and participate in next steps. Subsequently in January 2004, the Centers for Medicare & Medicaid Services (CMS) funded several of the action items articulated in the conference as a special project. The ESRD Network of Texas, Inc. (Network #14) served as the lead Network in this initiative for the Forum of ESRD Networks. The project was named *Decreasing Dialysis Patient-Provider Conflict* **(DPC).**

PURPOSE & GOALS

The Decreasing Dialysis Patient-Provider Conflict (DPC) Project was a coordinated, national effort by the ESRD community to understand, educate, and provide resources to the providers of dialysis services to better cope with the issue of conflict in dialysis facilities. The project goals were to help create safe dialysis facilities, provide training resources for handling conflict, improve patient-provider relations, improve patient-provider satisfaction with the dialysis experience, and foster national collaboration on the development of a DPC Taxonomy & Glossary and in approaches to reduce conflict.

Description

NATIONAL TASK FORCE

The National Task Force, comprised of 19 members, met three times during 2004 - 2005 in Baltimore, Maryland, to plan, review, and approve the work of the four subcommittees. Members also participated in and/or arranged for testing in their facilities. A list of the members is attached in Appendix A.

In January 2004 the work of the Decreasing Dialysis Patient-Provider Conflict (DPC) project commenced with the formation of a National Task Force of renal stakeholder representatives co-chaired by Richard Goldman, MD, and Glenda Harbert, ADN, RN, CNN, CPHQ. The DPC Task Force was charged with the following:
1. Articulate variables inherent in DPPC for further research
2. Review and build consensus to adapt the Network 17 glossary as a taxonomy for use in SIMS, VISION, the Core Data Set, and provider training and test usefulness
3. Describe the rights & obligations of providers and patients in an entitlement system
4. Develop and test and produce a DPC Toolbox including a Crisis Intervention Brochure & Poster
5. Disseminate this toolbox to dialysis facilities and provide training through the ESRD Networks.

The following four DPC subcommittees were formed to address the identified action items. Memberships lists are attached in Appendices A and B.
1. Ethical, Legal, and Regulatory Subcommittee
2. Taxonomy and Glossary Subcommittee
3. Variables of Interest Subcommittee
4. DPC Toolbox Subcommittee

The DPC Project relied heavily on the participation, experience, and expertise of individuals who represent the ESRD stakeholder community. These individuals have worked on one or more of the four DPC Subcommittees in researching, developing, and writing the assigned material. In addition to this Subcommittee work,
∞ the DPC Taxonomy and Glossary was field tested with 330 renal professionals. The testing of the Taxonomy and Glossary involved pre-post testing with a 10-question, multiple-choice form.
∞ the contents of the DPC toolbox were tested with 36 dialysis facilities in three ESRD Networks in Michigan, North Carolina, and Texas. This testing phase required each participating facility to train its staff in the use of DPC toolbox products and to complete an evaluation of the effectiveness and ease of use of each tool.

The DPC Project dissemination was completed in June 2005 with training for ESRD Networks via WebEx sessions that were taped for future use. The DPC Poster was disseminated to all 4494 dialysis facilities in the US with a cover letter announcing the project. In this same time period DPC toolboxes were shipped to each ESRD Network in sufficient numbers to accommodate existing facilities with a small supply for new facilities. ESRD Networks received a small stipend from the DPC Project to conduct training within their Network area during the following 12 months.

REPORT OF TAXONOMY & GLOSSARY SUBCOMMITTEE

The Subcommittee, chaired by Wendy Funk- Schrag, LMSW, ACSW, was formed to examine and adapt prior work of the ESRD Network #17 and to build consensus among the renal stakeholders for a national Taxonomy and Glossary to describe the behaviors and actions of both dialysis patients and staff. The categories, terms and definitions adopted by the subcommittee and approved by the Task Force were then tested for both applicability to the experiences of dialysis staff and for feasibility of implementation and use at the facility level.

The DPC Taxonomy & Glossary (T&G) Test

Methods
The DPC Taxonomy and Glossary was field tested with 330 renal professionals that included facilities in the Large Dialysis Organizations (LDO's) and one Council of Nephrology Social Workers. The testing of the Taxonomy and Glossary involved pre-post testing with a 10-question, multiple-choice form. A PowerPoint presentation was utilized to provide background and to introduce the Taxonomy and Glossary to participants. Case studies were also utilized to test the assignment of the Taxonomy and Glossary to the examples.

Observations
The pre- post testing presented various case studies and asked participants to choose the correct taxonomy or term. The poorest score where both the pre- and post-presentation answer was incorrect (with 27% incorrect) was this question "A [patient] refuses to come to dialysis at least once per week". Answer choices included *other patients at risk*, *patient at risk,* and *facility at risk*. The correct answer *was all of above*. Poor understanding of this case study may have occurred because no criteria were established to determine when non-adherence changes from the category of *risk to self* only to *risk to others & facility*. The Task Force believed that this determination could only be made individually at the facility level since many variables would impact that decision.

The second poorest score for both pre- and post presentation (with 12% incorrect) was the question "A staff member refuses a patient's request to have another person stick him." The correct answer is *staff verbal abuse*. Staff may have chosen the answer "[patient] had no right to make the request" because of

existing facility policies and procedures prohibiting patient choice in cannulation. There was variation on this answer between LDO's units that may reflect differing policies. The need for congruence between facility policies and the DPC Project is emphasized in the DPC Manual.

The third poorest score with 9% for both incorrect was received on a question regarding lack of payment. There likely was confusion regarding the answer indicating that staff who provide inadequate or inaccurate information place the *patient and facility at risk*. This uncertainty highlights the problems that may arise from grouping staff in with patients in all the categories and demonstrates the novelty of inclusion of staff along with patients in the Taxonomy and Glossary.

There was very high agreement on the importance and feasibility of the taxonomy and glossary. Training on verbal/written threat and nonadherence received the highest scores for importance. Training on adherence and verbal/written threat and abuse were selected as the most useful in the clinic, while damage/theft and non adherence were deemed the most feasible to measure. Using a scale of 1 to 5, with 5 being the highest, non adherence received a score of 4.3 when the following was considered, the "T & G terms describe conflicts seen or experienced in dialysis clinic". This result speaks to the relevance and usefulness of the Taxonomy and Glossary tool. See Appendix C.

REPORT OF TOOLBOX SUBCOMMITTEE
The Toolbox subcommittee developed a conflict resolution model utilizing the word *conflict* as a mnemonic that is the foundation of staff training components including the interactive software. Chaired by Mark Meier, MSW, LICSW the subcommittee met once and then worked during the period of May 2004 through January 2005 to develop and complete the DPC Toolbox. Contents include a manual with suggested program implementation using three steps with a Trainers Guide for staff training, brochures, pocket cards and a poster reinforcing the *CONFLICT* Resolution mnemonic, interactive training software, QI Tools, and other resources.

Report of the Toolbox Test
The DPC Toolbox test was conducted from January 15 through March 15, 2005. Test objectives and the testing plan were formulated in advance and submitted to CMS per contract. A total of **36** facilities trained **223** staff in three ESRD Networks to complete the DPC Toolbox test. A full report of the Toolbox test is attached in Appendix D.

OBJECTIVES

The first objective regarded the characteristics of the facilities in which the toolbox test was conducted. Testing in both Large Dialysis Organization (LDO) and independent facilities as well as both metropolitan and rural settings was planned. While both rural and metropolitan facilities were included, only one independent facility participated. Emphasis was placed on LDO buy-in and thus different corporations were engaged in the three test regions. Network 11 in the Upper Midwest trained seven Fresenius Medical Care (FMC) facilities, Network 6 in the Carolinas and Georgia trained six DaVita facilities and one independent facility, and Network 14 in Texas trained 15 Gambro Healthcare (GHC) facilities for a total of **36** test facilities.

A second test objective was to determine program feasibility at the facility level. Staff of the three Networks utilized a uniform Training Agenda and materials during a full day meeting to train 51 facility and regional staff. DPC project background was presented and the draft DPC Provider Manual reviewed in detail. Additionally, both group activities and discussion was employed. The

Manual included a three step suggested implementation plan. Evaluations of the training day from all three Networks were generally positive; however, several respondents (25%) did not feel adequately prepared to return to their facilities and implement the program. In follow-up discussions, many participants stated that they were very anxious about the aggressive time frame of the test and believed that anxiety coupled with the importance of the test was responsible for the negative responses regarding adequate preparation.

Other objectives were to measure effectiveness in reducing conflict and to measure utility of the tool as well as obtain facility user input regarding the program and the tools. Both Administrative and Staff survey instruments utilized various methods including Likert scale type questions and open-ended questions that requested specific comments. Test facilities were asked to return one staff Toolbox Evaluation for each person that was trained and one Administrative Evaluation.

It was apparent to the Networks in advance that the short testing period would not allow for measurement of effectiveness in decreasing conflict. Test facilities were requested to share conflict data at 6 month & 12 month intervals to allow for a delayed evaluation of this objective.

PROGRAM EVALUATION

Several evaluation tools were utilized to obtain information from all levels of staff about each component of the Toolbox. Eighteen (18) facilities returned an Administration Evaluation from three Networks (Networks 6, 11, and 14.) Reportedly 223 staff members went through the training. These staff members were trained by various disciplines ranging from facility secretaries to clinical managers. Interestingly, some trainers reported discomfort in being thrust into the role, stated that they were not experienced as trainers and complained of being required to prepare for the training on their own time. Only three of eighteen Medical Directors attended training.

Key findings from the DPC Toolbox test include the following:
- ∞ Only **12.5%** of facilities reported offering previous formal training in the unit for conflict management
- ∞ **100%** said that their clinics would be willing to adopt one or more of the recommendations
- ∞ **50%** believed that they would see a decrease in conflict with continued use of the DPC Program and Toolbox
- ∞ **62.5%** thought that it was likely that they will continue to use the DPC Program and Toolbox after the testing phase was completed

LESSONS LEARNED

As was previously mentioned, the short test period was a limitation and a lesson learned for the dissemination of the DPC project nationally. A recommendation

for a several month Implementation Plan was incorporated into the DPC Manual and emphasized in training of the ESRD Networks.

Attention to the comfort level and preparation of the person asked to provide the training at the facility level should not be underestimated. The unit Social Worker is not necessarily the first choice to be the trainer. A person who is comfortable presenting and who has some experience in education will be most effective. Corporations should be encouraged to utilize staff educators if available.

The 50% response rate by participants that were trained may indicate that the evaluation tools were too lengthy and complex. Several commented negatively about the time required to complete the training and the evaluations. Future projects should use short, concise evaluation tools. A problem of inconsistent scales in the evaluation was identified during data analysis and this may have impacted the results of hurried staff that may not have noticed the change.

The interactive training software, comprised of two courses based upon the Conflict Resolution model, was rated highly by the participants. It is designed for individual use, requires no trainer, and produces a training certificate upon completion. Numerous revisions were made to the software as a result of and during the test.
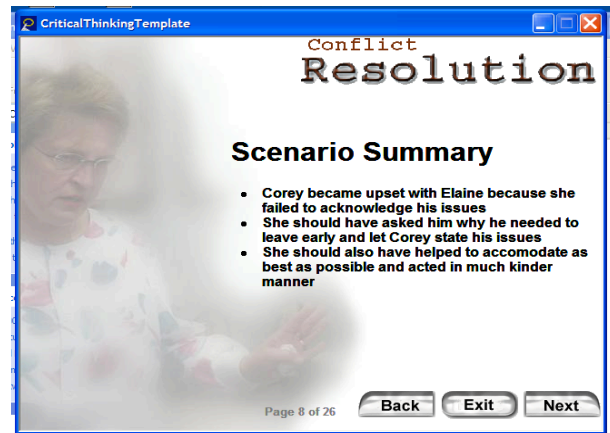
The services of the Academy for Educational Development (AED) were employed to assist in the editorial work and to convert the Modules to a Trainer format with Trainer Tips throughout. When professionally printed it will be easier to use and follow than the large binders that were used in the test.

Although a small sample, the test provides an indication of the current state of conflict management in dialysis facilities in the United States since it included facilities from the three largest LDOs. The evaluations confirm lack of conflict training as identified by the DPPC stakeholders with only **12.5%** offering previous formal training in the unit for conflict management. Additionally, only **25%** reported tracking conflict in quality improvement (QI), with **29%** reportedly observing trends in the short test period.

Overall:
- ∞ **72%** of the staff agreed that after receiving the DPC information they felt better trained to handle conflict

- ∞ **70%** agreed that they felt more confident in handling conflict
- ∞ **74%** felt they would be able to recall and utilize some aspect of the DPC training
- ∞ **72%** agreed that the training and materials had resulted in an increased level of discussion about how to successfully cope with conflict among the clinic staff

The stakeholders identified a lack of a defined methodology for collecting data about Dialysis Patient-Provider Conflict as a deep driver in the challenges to making progress in this area. It is hoped that the development of the DPC Taxonomy & Glossary and QI Tools incorporating it will support progress in the area of defined data collection for future work and internal quality improvement.

REPORT OF THE ETHICAL, LEGAL, AND REGULATORY SUBCOMMITTEE

The Ethical, Legal, and Regulatory (ELR) Subcommittee, chaired by William Winslade, JD, PhD, met on April 6, 2004, in Houston, Texas. The work of the Subcommittee resulted in a document entitled, "Decreasing Dialysis Patient-Provider Conflict: National Task Force Position Statement on Involuntary Discharge." The paper examines entitlement in the context of the ESRD Medicare Program and explores the rights and obligations of patients and providers. The Executive Summary is provided as Attachment E.

The "Decreasing Dialysis Patient-Provider Conflict National Task Force Position Statement on Involuntary Discharge" included the following 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 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.
   - ∞ 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 necessary 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 review records for transfer AND 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 a face-to-face meeting with the potential provider, patient and family and use of treatment trials and behavior agreements.

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

The Position Statement was adopted by the DPC National Task Force on January 14, 2005, and has been endorsed by the following renal stakeholders:

American Association of Kidney Patients
American Nephrology Nurses' Association

Gambro Healthcare
National Association of Nephrology Technicians
National Kidney Foundation
National Renal Administrators Association
Renal Physicians Association

At this time, the ELR Subcommittee is pursuing publication of the Position Statement in both peer-reviewed journals and law review journals.

REPORT OF THE VARIABLES OF INTEREST SUBCOMMITTEE

A list of potential areas for research and areas that may factor uniquely into conflict has been drafted and will be explored in a manuscript by Subcommittee Chair Barry Hong, PhD, ABPP. Dr. Hong has developed a DPC Assessment and Intervention Roadmap, which will be supplemented by a step-by-step process for psychiatric referral for patients. (See Attachment F.)

PRESENTATIONS

Presentations have been made to the Professional Organizations to raise awareness and prepare the community for implementation of the DPC Project and receipt of the Toolbox.

1. 2004 CMS/Forum of ESRD Networks' Annual Meeting, Baltimore, MD, March 2004 – Richard S. Goldman, MD, and Glenda Harbert, RN, CNN, CPHQ
2. 2004 Forum Membership Meeting, Baltimore, MD, March 2004 – Richard S. Goldman, MD, and Glenda Harbert, RN, CNN, CPHQ
3. American Nephrology Nurses' Association (ANNA) meeting in Washington, DC, April 16, 2004 - Glenda Harbert, RN, CNN, CPHQ
4. Task Force members attended the ANNA National Symposium on May 17, 2004. The project background, project plans, and taxonomy were presented, followed by discussion of situations dealt with in facilities of the participants.
5. National Renal Administrator Association (NRAA) meeting in Cancun, Mexico, in May 2004 - Glenda Harbert, RN, CNN, CPHQ
6. The DPC Project Update was shared with the Forum Board of Directors on July 23-25, 2004.
7. Overview of the DPC Project, 2004 AAKP Annual Convention on September 2-5, 2004 - Task Force Co-Chair Richard S. Goldman, MD
8. Network 8 Annual Meeting October 2004, Memphis - Mark Meier, MSW, LICSW
9. Network 11 Annual Meeting, 10/8/04- Glenda Harbert, RN, CNN, CPHQ
10. Network 14 Annual Meeting, 10/16/04- Glenda Harbert, RN, CNN, CPHQ
11. Network 7 Annual Meeting, 11/18/04- Glenda Harbert, RN, CNN, CPHQ

12. National Kidney Foundation (NKF) Meeting, 10/30/04- Mark Meier, MSW, LICSW
13. American Renal Associates Medical Directors Meeting.Boston-10/8/05- Richard S. Goldman, MD
14. 2005 CMS/Forum of ESRD Networks' Annual Meeting, Baltimore, MD, March 2005 - Richard S. Goldman, MD
15. Minnesota CNSW meeting, Minneapolis, MN, March 2005 - Mark Meier, MSW, LICSW
16. Renal Physicians Association (RPA) 2005 - Richard S. Goldman, MD
17. American Nephrology Nurses' Association (ANNA) National 05 - Mark Meier, MSW, LICSW, and Emily Hodgin, BSN, RN, CNN, CPHQ
18. Virginia state American Nephrology Nurses' Association (ANNA) 3/18/05 - Emily Hodgin, BSN, RN, CNN, CPHQ
19. National Kidney Foundation (NKF) 2005 Annual Meeting, Washington DC, May 2005 – Richard S. Goldman, MD
20. National Kidney Foundation (NKF) 2005 Annual Meeting, Washington DC, May 2005- Mark Meier, MSW, LICSW
21. "Interventions for Non-compliance" - Wendy Funk-Schrag, LMSW, ACSW
    Audience: RCG social workers and our area managers (nurses) and clinical educators (nurses):
    - ∞ February 16, 2005: Houston, TX
    - ∞ February 17, 2005: Corpus Christi, TX
    - ∞ February 23, 2005: El Paso, TX
    - ∞ February 24, 2005: Dallas, TX
    - ∞ June 16, 2005: Chicago, IL
    Audience: nurses with a few social workers and dietitians, NKF meeting in Cedar Rapids, Iowa on April 17, 2005

It is expected that such presentations will continue as the project is utilized and data becomes available from the standardized data collection.

CONCLUSIONS

It is reasonable to expect that conflict will continue to be a concern in light of the rapid growth of the in-center hemodialysis population, along with the concomitant pressures of staffing shortages, reimbursement issues, industry consolidation, and organ shortages. The ESRD Networks are uniquely positioned to collaborate with the providers of dialysis care to address conflict in the dialysis facility as leaders in the quality improvement aspect of ESRD care. The full impact of the DPC Project will not be realized for some time since delivery of the DPC Toolbox and training of the facility staff will be completed over the ensuing 12 months.

RECOMMENDATIONS

1. CMS should recommend implementation and use of the DPC products to the dialysis providers

2. CMS should continue collaboration with the Forum of ESRD Networks and the provider community to address conflict
3. CMS should support updates, enhancements, dissemination, and training on new aspects of conflict management as they become available.

This document was prepared under contract with the Centers for Medicare & Medicaid Services (CMS Contract # 500-03-NW14).

APPENDICES

APPENDIX A
DPC TASK FORCE MEMBERS

Richard S. Goldman, MD	Task Force Co-Chair Forum Board of Directors; Renal Physicians Association
Glenda F. Harbert, RN, CNN, CPHQ	Task Force Co-Chair Executive Director, ESRD Network of Texas, Inc.
Karin Anderson-Barrett, BSN, RN, JD	Attorney, DCI Legal Department, Dialysis Clinic, Inc.
Elaine Colvin, RN, BSN, MEPD	Immediate Past Chairperson of ANNA's Ethics Committee
Sandie Guerra Dean, MSW, LICSW	Corporate Social Worker, Fresenius Medical Care NA
Cammie Dunnagan	ESRD Software Implementation Manager Computer Sciences Corporation, Inc.
Brenda Dyson	President, American Association of Kidney Patients
Clifford Glynn, CHT	President, National Association for Nephrology Technicians/Technologists
Kay Hall, BSN, RN, CNN	Director Regulatory Affairs/Licensure and Certification Gambro Healthcare U.S.
Barry A. Hong, PhD, ABPP Psychiatry	Professor of Medical Psychology, Department of Washington University School of Medicine
Liz Howard, RN, CNN	Director of Policies and Procedures & Adverse Patient Occurrences DaVita, Inc.
Mark Meier, MSW, LICSW	Consumer Services Coordinator Renal Network of the Upper Midwest, Inc.
Ida Sarsitis	ESRD Requirements and Liaison Manager Computer Sciences Corporation, Inc.
Wendy Funk-Schrag, LMSW, ACSW	Patient Services Manager, Renal Care Group National Kidney Foundation Council of Nephrology Social Workers
Ann Stivers	People Services Manager, DaVita, Inc. National Renal Administrators' Association (NRAA)
Arlene Sukolsky	Executive Director, TransPacific Renal Network

Lisa Taylor, BSN, RN	Executive Director, ESRD Network #12
Sandra Waring MSN, CNN, CPHQ	Director of Quality Management, ESRD Network #2
William Winslade, PhD, JD	James Wade Rockwell Professor of Philosophy of Medicine, Professor of Preventive Medicine and Community Health and Professor of Psychiatry and Behavioral Sciences, University of Texas Medical Branch, Galveston, Texas; and Distinguished Visiting Professor of Law, University of Houston Health Law and Policy Institute
Janet Crow, MBA	Administrator, Forum of ESRD Networks

Ethical, Legal, and Regulatory Subcommittee
William Winslade, PhD, JD, Chair
Karin Anderson-Barrett, BSN, RN, JD
Elaine Colvin, RN, BSN, MEPD
Glenda Harbert, RN, CNN, CPHQ
John Newmann, PhD, MPH
Barry Straube, MD
Denise Rose, JD (intern to Dr. Winslade)

Toolbox Subcommittee
Mark Meier, MSW, LICSW, Chair
Elaine Colvin, RN, BSN, MEPD
Clifford Glynn, CHT
Sandie Guerra Dean, MSW, LICSW
Emily Hodgin, BSN, RN, CNN, CPHQ
Kathi Niccum, EdD
Ramiro Valdez, MSW, PhD

Taxonomy and Glossary Subcommittee
Wendy Funk-Schrag, LMSW, ACSW, Chair
Sandie Guerra Dean, MSW, LICSW
Kay Hall, BSN, RN, CNN
Catherine Haralson
Mark Meier, MSW, LICSW
William Winslade, PhD, JD

Variables Subcommittee
Barry A. Hong, PhD, ABPP, Chair
Richard S. Goldman, MD
Mark Meier, MSW, LICSW

APPENDIX C

TAXONOMY AND GLOSSARY

<u>When conflict occurs in the dialysis facility, the contributing behaviors can be organized into three categories based on who is placed "at risk":</u>
1. Behaviors by a patient, staff, family members or others may result in placing the **patient's** own health, safety and well being at risk.
2. Behaviors by patients, staff, family members or others may put the safety and effective operations of **the dialysis facility** at risk.
3. Behaviors by patients, staff, family members or others may put the health, safety or well being of **others** at risk. Others include other patients, staff or anyone else in the dialysis facility.

The table below includes behaviors that define types of conflict. This list is not all-inclusive but explains the main behavioral contributions to conflict and specific examples of behavior by patients, staff, family members or others that contribute to putting the patient, the facility or others at risk.

GLOSSARY	TAXONOMY		
Term & Definition	**Patient at Risk**	**Facility at Risk**	**Others at Risk**
1. Nonadherence: Noncompliance with or nonconforming to medical advice, facility policies and procedures, professional standards of practice, laws and/or socially accepted behavior toward others (Golden Rule).	**a. Patient Example:** Missed or shortened treatments may result in need for hospitalization or death. **b. Staff Example**: Negative comments or scolding of a patient for nonadherence that may lead to conflict. Withholding opportunity to reschedule missed treatment.	**c. Patient Example:** Unreasonable refusal to allow certain staff to provide care, causing disruption in facility schedule or refusing to follow clinic rules and policies. **d. Staff Example:** Unreasonable refusal to care for a particular patient, refusal to enforce policies and procedures, unauthorized manipulation or change to a prescribed treatment or physician's orders.	**e. Patient Example:** Actions that encourage other patients to miss treatments or not follow treatment requirements or clinic policies **f. Staff Example:** Inconsistent enforcement of dialysis schedule and/or not providing full dialysis treatments. Not following facility policies and procedures that would provide intervention for patients' nonadherence.
2. Verbal/written abuse: Any words (written or spoken) with an intent to demean, insult, belittle or degrade facility or medical staff, their representatives, patients, families or others.	**a. Patient Example:** Name-calling, insults, use of obscenities, verbal or written sexual harassment. **b. Staff Example:** Demeaning words directed at patients, use of disrespectful language.	**c. Patient Example:** Verbal incidents that cause disruption or delay in the ongoing treatment of other patients. **d. Staff Example:** Insults or demeaning words directed at other staff, causing disruption or delay in the facility operations.	**e. Patient Example:** Verbal or written abuse directed at other patients or others in the facility. **f. Staff Example:** Verbal or written abuse directed at others at the facility.
3. Verbal/written threat: Any words (written or spoken) expressing an intent to harm, abuse or commit violence directed toward facility or medical staff, their representatives, patients, families or others.	**a. Patient Example:** Threatening statements directed toward others that intimidate or cause fear. **b. Staff Example:** Threatening statements that cause patients to feel intimidated, fearful or otherwise unsafe receiving treatment in the facility.	**c. Patient Example:** Threats that result in the need for facility use of additional resources (e.g. security guard) for the safety and protection of patients, staff and visitors. **d. Staff Example:** Threats directed at a patient or patients that result in patient transfer to another facility. Legal action against staff or the facility may occur as a result of a verbal threat.	**e. Patient Example:** Threats that create an unsafe environment for other patients, staff and others. **f. Staff Example:** Threats that create an unsafe environment for patients, staff and others.

Term & Definition	Patient At Risk	Facility At Risk	Others at Risk
4. Physical threat: Gestures or actions expressing intent to harm, abuse or commit violence toward facility or medical staff, their representatives, patients, families or others.	**a. Patient Example:** Threat of self-harm (e.g. suicide, pulling out needles or catheter) or other actions such as raising one's hand as if to strike. **b. Staff Example:** Threatening to hurt patient during needle insertion or other threatening actions such as threatening to perform a procedure without patient's consent.	**c. Patient Example:** Threats that result in need for facility use of additional resources (e.g. security guard) for the safety and protection of patients, staff and visitors **d. Staff Example:** Turnover at the facility caused by staff unplanned absences or resignations due to unpleasant and/or unsafe work environment.	**e. Patient Example:** Threatening to use and/or possession of a weapon or any instrument capable of injuring others with the intent to intimidate or harm others, either in the facility or on the premises. **f. Staff Example:** Threatening to use and/or possession of a weapon or any instrument capable of injuring others with the intent to intimidate or harm others, either in the facility or on the premises.
5. Physical harm: Any bodily harm or injury, or attack upon facility or medical staff, their representatives, patients, families or others.	**a. Patient Example:** Any incidents of physical harm such as changing machine settings, pulling own bloodlines, refusing medication. **b. Staff Example:** Withholding treatment from the patient without just cause. Intentionally causing pain or injury to patient or patient's access.	**c. Patient Example:** Incidents that result in law enforcement intervention and facility use of additional resources (e.g. security guard) for the safety and protection of patients, staff and visitors. **d. Staff Example:** Turnover at the facility caused by staff unplanned absences or resignations due to unpleasant and/or unsafe work environment.	**e. Patient Example:** Incidents of physical harm to others in the facility (e.g. other patients, visitors, medical or facility staff), including sexual harassment. **f. Staff Example:** Incidents of physical harm to others in the facility (e.g. other patients, visitors, medical or facility staff).
6. Property damage/ theft: Theft or damage to property on premises of ESRD facility	**a. Patient Example:** Vandalism or damage to dialysis equipment or facility premises. **b. Staff Example:** Stealing from patient(s).	**c. Patient Example:** Intentional and malicious damage of equipment/property. **d. Staff Example:** Intentional and malicious damage of equipment/property.	**e. Patient Example:** Stealing or damaging the property of others. **f. Staff Example:** Stealing or damaging the property of others.
7. Lack of payment: Refusal to maintain or apply for coverage or misrepresentation coverage.	**a. Patient Example:** Refusing to apply for insurance coverage for which patient is eligible. **b. Staff Example:** Intentionally providing inaccurate or inadequate information to a patient about insurance resources.	**c. Patient Example:** Withholding or refusing to deliver insurance payments or co-pays to facility. **d. Staff Example:** Uninsured or underinsured patients affect facility's reimbursement for services provided and facility's ability to provide adequate staffing."	**e. Patient Example:** Lack of payment may result in the elimination of some patient services, for example, preferred dialysis shift schedule. **f. Staff Example:** Can affect facility's solvency and result in reduced hours, layoffs or reassignment to another facility location if facility is unable to operate due to inadequate revenues."

Report of Toolbox Test

The DPC toolbox was developed by a Workgroup (list attached in Appendix A) chaired by Mark Meier, MSW during the period of May 2004 through January 2005. The DPC Toolbox test was conducted from January 15 through March 15, 2005. DPC test objectives and the testing plan were formulated in advance and submitted to CMS per contract. A total of 36 facilities in three ESRD Networks participated in the DPC Toolbox Test.

OBJECTIVES
The first objective regarded the characteristics of the facilities in which the toolbox was tested. Testing in both Large Dialysis Organization (LDO) and independent facilities as well as both metropolitan and rural settings was planned. While both rural and metropolitan facilities were included, only one independent facility participated. Emphasis was placed on LDO buy-in and thus different corporations were engaged in the three test regions. Network (NW) 11 in the Upper Midwest trained seven Fresenius Medical Care (FMC) facilities, Network 6 in the Carolinas and Georgia trained six DaVita facilities and one independent facility, and Network 14 in Texas trained 15 GHC facilities for a total of **36** test facilities.

A second test objective was to determine program feasibility at the facility level. A uniform Training Agenda and materials were utilized to train 51 facility and regional staff in a full day meeting with test facilities by staff of the three respective Networks. DPC project background was presented and the draft DPC manual reviewed in detail. Additionally, both group activities and discussion was employed. The manual included a three step suggested implementation plan. Evaluations of the training day from all three Networks were generally positive; however, several respondents (25%) did not feel adequately prepared to return to their facilities and implement the program. In follow up discussions, many participants stated that they were very anxious about the aggressive time frame of the test and believed that anxiety coupled of the importance of the test was responsible for the negative responses regarding adequate preparation.

Other objectives were to measure effectiveness in reducing conflict, measure utility of and obtain facility user input regarding the program and the tools. Both Administrative and Staff survey instruments utilized various methods including Likert scale type questions and open-ended questions that requested specific comments. Test facilities were asked to return one staff Toolbox Evaluation for each person that was trained and one Administrative Evaluation.

It was apparent to the Networks in advance that the short testing period would not allow for measurement of effectiveness in decreasing conflict. Test facilities were requested to share conflict data at 6-month & 12-month intervals to allow for a delayed evaluation of this objective.

PROGRAM EVALUATION

Administration Evaluation

Eighteen (18) facilities returned an administration evaluation from three Networks (Networks 6, 11, and 14). Reportedly **223** staff members went through the training. These staff members were trained by various disciplines ranging from facility secretaries to clinical managers. Interestingly, some trainers reported discomfort in being thrust into the role, stated that they were not experienced as trainers and complained of being required to prepare for the training on their own time. Only three of eighteen medical directors attended this training.

It appears that some facilities, perhaps pressed by the timelines of the test or the extensive evaluation tools, did not require each participant to complete the Toolbox Evaluation since 223 staff members were trained and only 102 Staff Evaluations were received. The impact of this suboptimal (< 50%) response rate on the results is not known. An average of **3** hours to complete the training was reported with a wide range of 1½ to 6 hours.

When rating the effectiveness of the program, only **50.0**% of Administrators reported an observed increase in staff comfort in dealing with conflict situations, **47**% an increase in staff competence in dealing with conflict situations, and **61**% observed their staff approaching conflict situations in a more professional manner. It should be noted that no test facilities were asked or able to complete the entire program due to time limitations. Additionally the Administrative results in this area differ considerably from reports of the staff that completed the evaluation (see page 6).

Out of the 13 DPC Toolbox components
∞ **83**% rated the DPC "Six Steps for Resolving Conflict" as the most effective tool
∞ **47**% of the evaluators rated the DPC Bibliography as least effective

In rating the ease of use of the Provider Manual:
∞ **87**% of the evaluators rated the DPC Provider Manual easy to follow
∞ **85**% were willing to make policy and procedure revisions in an effort to more effectively deal with conflict situations
∞ **59**% rated both the "Tips for Diffusing Anger" and "Six Steps for Resolving Conflict" as the most user-friendly of the DPC Toolbox Components and effective tools to deal with conflict

Quality Improvement

∞ **25**% of the facilities reported monitoring conflict on a formal basis
∞ **29**% discovered patterns of conflict when using the QI Tracking Tools
∞ **75**% found the Tracking Tools easy to use and understand
∞ **75**% of the evaluators thought that it is important to track conflict in the clinic using QI tools

Other Information

Only **12.5**% of facilities reported offering previous formal training in the unit for conflict management. **100**% said that their clinics would be willing to adopt one or more of the recommendations. **50**% believed that they would see a decrease in conflict with continued use of the DPC program and Toolbox. **62.5**% thought that it was likely that they will continue to use the DPC program and Toolbox after the testing phase was completed.

Overall, there were problems in some of the facilities during training due to computer inadequacies, missing Toolbox components, and lack of time for the staff to complete the various modules.

Official Courseware Evaluation Form- Software

90 evaluations were returned from 3 Networks (Networks 6, 11, and 14).

When rating user friendliness
- ∞ **98**% found the course easy to move from page to page
- ∞ **99**% were able to quickly figure out how to use the main buttons
- ∞ **99**% found the screens well organized
- ∞ **99**% found the background pictures appropriate
- ∞ **100**% did not find the screens overloaded
- ∞ **96**% felt that the questions in these training courses helped them to memorize the information
- ∞ **91**% enjoyed taking course #1
- ∞ **91**% enjoyed taking course # 2
- ∞ **97**% found the videos helpful
- ∞ **90**% said that the courses helped them to feel more confident in their jobs
- ∞ **93**% felt that the questions in this course helped them to become better at solving difficult problems

Overall, the staff seemed to enjoy the scenarios but found it difficult to make the time necessary for completing this course.

(DPC) Toolbox Evaluation
DPC Poster
- ∞ **62**% of the evaluators found the DPC Poster useful
- ∞ **67**% felt that it prompted them to think about new ways to handle conflict
- ∞ **67**% thought that it would remind them to think about the DPC Conflict Model

DPC Brochure
- ∞ **63**% of the evaluators found the DPC Brochure useful
- ∞ **67**% felt that the brochure helped them to think about dealing with conflict in a step-by-step manner
- ∞ **67**% thought the brochure language and examples provided them with an understanding of the DPC Conflict Resolution model

DPC Pocket Card
- ∞ **54**% of the evaluators felt that the Pocket Card would be useful as they try to decrease conflict in the clinic
- ∞ **50**% of the staff said they would be willing to carry the pocket card during their shifts and refer to it as conflicts occurred
- ∞ A number of evaluators felt that the cards were too large and felt that reaching into pockets, while in the center, should be discouraged

DPC Bibliography
- ∞ **50**% evaluated the bibliography as useful to try to decrease conflict in the clinic

- ∞ **52%** said that bibliography appeared relevant as they sought to better understand cope with conflict
- ∞ **42%** indicated that they would likely take the time to locate and read the articles from the bibliography

DPC Taxonomy
- ∞ **66%** of the evaluators felt that the taxonomy will be useful to them as they tried to decrease conflict in the clinic,
- ∞ **67%** said that the conflicts that they had seen or experienced fit the categories described in the taxonomy
- ∞ See discussion in lessons learned

DPC Glossary
- ∞ **64%** of the staff indicated that the glossary would be useful to them as they try to decrease conflict in the clinic
- ∞ **62%** agreed that the glossary terms described the conflicts that they had seen or experienced in the dialysis clinic
- ∞ See discussion in lessons learned

DPC Interactive Web-based Training
- ∞ **62%** of the evaluators indicated that the Web-based training would be useful to them as they try to decrease conflict in the clinic
- ∞ **60%** of the staff agreed that the conflict scenarios depicted were realistic and similar to what they had seen in their dialysis clinics
- ∞ These data are negatively incongruent with a separate more complicated evaluation that included an evaluation of the software designed by the educational firm that produced the software. See page 3 *Official Courseware Evaluation Form- Software*
- ∞ Staff found the program hard to access and hear

DPC Tips and Ideas
- ∞ **70%** of the evaluators agreed that the tip sheets would be useful as they tried to decrease conflict in the clinic
- ∞ Staff enjoyed the role playing

DPC Quality Improvement Tracking Tool
- ∞ **63%** of the evaluators agreed that the Documentation Form would be useful as they tried to decrease conflict in the clinic
- ∞ **68%** agreed that it is important to utilize QI tools to understand and decrease the causes of conflict
- ∞ **67%** thought that the Tracking Tool will be useful in tracking the number and types of conflict occurring in the facility

Position Statement on Involuntary Discharge
- ∞ **68%** of the evaluators indicated the Position Statement would be useful to them as they try to decrease conflict in the clinic

- ∞ **65%** of the staff agreed that the Position Statement would help them to better understand the ethical, legal, and regulatory issues involved with involuntary patient discharge

Guide to Responding to the Top Ten Complaints
- ∞ **73%** agreed that the Top Ten guide would be useful to them as they try to decrease conflict in the clinic
- ∞ **72%** thought that the Top Ten guide provided them with new ideas for responding to potential conflict situations

Overall
- ∞ **72%** of the staff agreed that after receiving the DPC information they felt better trained to handle conflict
- ∞ **70%** agreed that they felt more confident in handling conflict
- ∞ **74%** felt they would be able to recall and utilize some aspect of the DPC training
- ∞ **72%** agreed that the training and materials had resulted in an increased level of discussion about how to successfully cope with conflict among the clinic staff

These positive responses by staff are in contrast with the evaluation of the Administrators who reported, when rating the effectiveness of the program:
- ∞ **50%** observed an increase in staff comfort in dealing with conflict situations
- ∞ **47%** observed an increase in staff competence in dealing with conflict situations
- ∞ **61%** observed their staff approaching conflict situations in a more professional manner
- ∞ It should be noted that no test facilities were ask or able to complete the entire program due to limitations of time

Lessons Learned

Time to fully implement the program: As was previously mentioned, the short test period was a limitation and a lesson learned for the roll out of the DPC project nationally. Recommendation for a several month Implementation Plan will be incorporated and emphasized in training of the ESRD Networks that will follow the test.

The Trainer: Attention to the comfort level and preparation of the person asked to provide the training at the facility level should not be underestimated. The unit Social Worker is not necessarily the first choice to be the trainer. A person who is comfortable presenting and who has some experience in education will be most effective. Corporations should be encouraged to utilize staff educators if available.

Evaluation Tools: The 50% response rate by participants that were trained may indicate that the tools were too complex and long. Several commented negatively about the time to complete the training and time to complete the evaluations. Future projects should use short, concise evaluation tools. A problem of inconsistent scales in the evaluation was identified during data entry and analysis and this may have impacted the results of hurried staff that may not have noticed the change.

Software: The Training Software is designed for individual use and requires no trainer. It was rated highly by the participants. Numerous revisions were made to the software as a result of and during the test that included but were not limited to:

∞ Reducing the RAM requirements

∞ Revamping the auto installer so that the average user can simply click "next, next, next, next…" until the program is installed. IT departments can choose a number of options important to them for program deployment.

∞ Creating a Read Me document for trouble shooting for IT professionals

∞ Adding three driver programs to allow the DPC program to work more efficiently

∞ Reformatting to create four DPC Courseware modules, two in high quality, and two in compatibility mode for lower version systems

∞ Enlarged and re-mastered the high quality videos to all be of a uniform large size in the critical thinking as well as information pieces

∞ Created a mechanism for the user to enter their name in the beginning of the course with printed completion certificate

DPC Manual:

> **Manual Usability:** The services of the Academy for Educational Development (AED) were employed to assist in the editorial work and to convert the Modules to a Trainer Format with Trainer Tips throughout. When professionally printed it will be easier to use and follow than the large binders that were used in the test.

> **Tools:** Although the Pocket Card is too large for the intended purpose, it will be included in the resources so that facilities can print them if desired. A CD will be included in the Toolbox that contains all the tools for ease of reproduction for use in training and QI.

> **Taxonomy & Glossary:** A separate test of only the Taxonomy and glossary was conducted previously in 9 groups with 330 renal professionals encompassing all LDO's. Results of that test were considerably more positive than the Taxonomy and Glossary portion of Toolbox Test. The cause of this discrepancy is unknown; however, it may be another indication of the need for additional time to complete the entire program.

Program Applicability: Although a small sample, the test provides an indication into the current state of conflict management in dialysis facilities in the United States since it included facilities from the three largest LDOs.

The evaluations confirm lack of conflict training as identified by the stakeholders with only **12.5**% offering previous formal training in the unit for conflict management. The Toolbox will provide a wide variety of training activities to each facility in the US. The ESRD Networks will support project roll out with training within 12 months in their region.

Additionally, only **25**% reported tracking conflict in QI; with **29**% reportedly observing trends in the short test period.

The stakeholders identified a lack of a defined methodology for collecting data about Dialysis Patient-Provider Conflict as a deep driver in the challenges to making progress in this area. It is hoped that the development of the DPC Taxonomy & Glossary and QI Tools incorporating it will support progress in the area of defined data collection for future work and internal quality improvement.

Numerous presentations have already been made to various Professional Organizations that has raised awareness and prepared the community for receipt of the Toolbox.

APPENDIX E

Decreasing Dialysis Patient-Provider Conflict
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, <u>both</u> 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 non-adherent behaviors that pose a risk only to them i.e., nonadherence 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.

In the early years of dialysis, those fortunate enough to have access to the treatment followed closely the recommendations of their providers. However, an increase 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 <u>may not be</u> 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 nonadherence (non-compliance) to treatment regimens. A workgroup organized by the **FORUM OF ESRD NETWORKS** designed a Centers for Medicare & Medicaid Services (CMS) funded national project with the purpose and goal of beginning to quantify the number of HD/PD patients involuntarily discharged, gain an understanding of the reasons(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 morbiditiy 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:

1. 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).
2. Behaviors, actions, or inactions by patients and/ or family, friends or visitors perceived to <u>put the safe and efficient operations</u> *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).
3. Behaviors, actions or inactions by patients and/ or family, friends or visitors that are perceived <u>to place the health, safety or well being of</u> *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. <u>These ethical obligations are not absolute</u> 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]
- 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" [viii]. 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 non-violent behaviors.

It is the position of this Task Force that terminating the patient/ provider relationship on the basis of behaviors that place <u>*only* the patient at risk</u> is unjustified. In the limited instances where the behaviors are so pervasive as to create significant <u>*financial & /or operational*</u> *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 NW 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 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.
   ∞ ~~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 <u>prospective providers</u> 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 review records for transfer AND 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 a face to face meeting with the potential provider, patient and family and use of treatment trials and behavior agreements.

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

The Position Statement was adopted by the DPC National Task Force on January 14, 2005, and has been endorsed by the following renal stakeholders:

<div align="center">

American Association of Kidney Patients
American Nephrology Nurses' Association
Gambro Healthcare
National Association of Nephrology Technicians
National Renal Administrators Association
Renal Physicians Association

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The opinions do not necessarily represent those of CMS.

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[1] Decreasing Dialysis Patient Provider Conflict Project National Task Force: 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).

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

[1] 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.

[1] 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.

[1] 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".

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

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

[1] Centers for Medicare & Medicaid Services ESRD Network Organization Manual 130.11

[1] Subpart U Conditions for Coverage of Suppliers of ESRD Services 405.2138

[i] Decreasing Dialysis Patient Provider Conflict Project National Task Force: 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.

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[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