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Designing A Collaborative Action Plan With the ESRD Stakeholders

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

Sponsored by:
The Forum of ESRD Networks

Prepared by:
Peter Schwartz, MD, PhD
Shari Rudavsky, PhD
Alexander N. Christakis, PhD

In Collaboration with:
Richard S. Goldman, MD
Glenda Harbert, RN, CNN, CPHQ

CWA Ltd. *Interactive Management Consultants*
WORLD HEADQUARTERS: 1770 E. Lancaster Avenue, #L5, Paoli, PA 19301 USA / Phone: 610-651-0414 / Fax: 610-651-2717 / www.CWAltd.com

The most meaningful thing a reader of this report can do is to embrace the voice of representative stakeholders in the ESRD community in their directive to “ensure that patients and providers in the dialysis units are able to resolve the issues of conflict and improve the quality of care of all patients in the units. Then ask one’s self “HOW CAN I GET INVOLVED?”

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EXECUTIVE SUMMARY

Twenty-five stakeholder representatives and twenty-one observers from twenty-seven organizations involved in the Dialysis Patient-Provider Conflict (DPPC) initiative of the Forum of ESRD Networks described sixty-seven challenges to improving the DPPC situation and proposed more than forty actions for addressing these challenges. The representatives were engaged in a collaborative action-planning conference that was designed and conducted employing a methodology founded in the systems sciences. Majority convergence was achieved on four important actions as the highest priority. These are:

- ***Adopt the setting of national curriculum/standard of education for dialysis technicians;***
- ***Increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives for DPPC;***
- ***Adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility; and***
- ***Leverage dialysis units to "make" social workers do what they are supposed to – not be clerical workers***.

Before the conference, interviews and a literature review had identified a wide variety of issues concerning DPPC and had articulated a range of approaches to ameliorate conditions that can lead to conflict in dialysis facilities.

Many interviewees noted that historical changes have altered the dialysis patient-provider relationship over the past three decades. In the early years of dialysis, those fortunate enough to have access to the treatment followed closely the recommendations of their providers. However, an influx of dialysis patients in recent years and a shift in the demographics of the patient population have changed that dynamic immeasurably. Staffing issues have also contributed to the situation, many interviewees said before the workshop commenced. 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 turned into a big business operation, with facilities aiming to streamline operations to make financial ends meet, units now rely on technicians to do the jobs nurses once performed. Technicians, who have had less training than nurses, may also

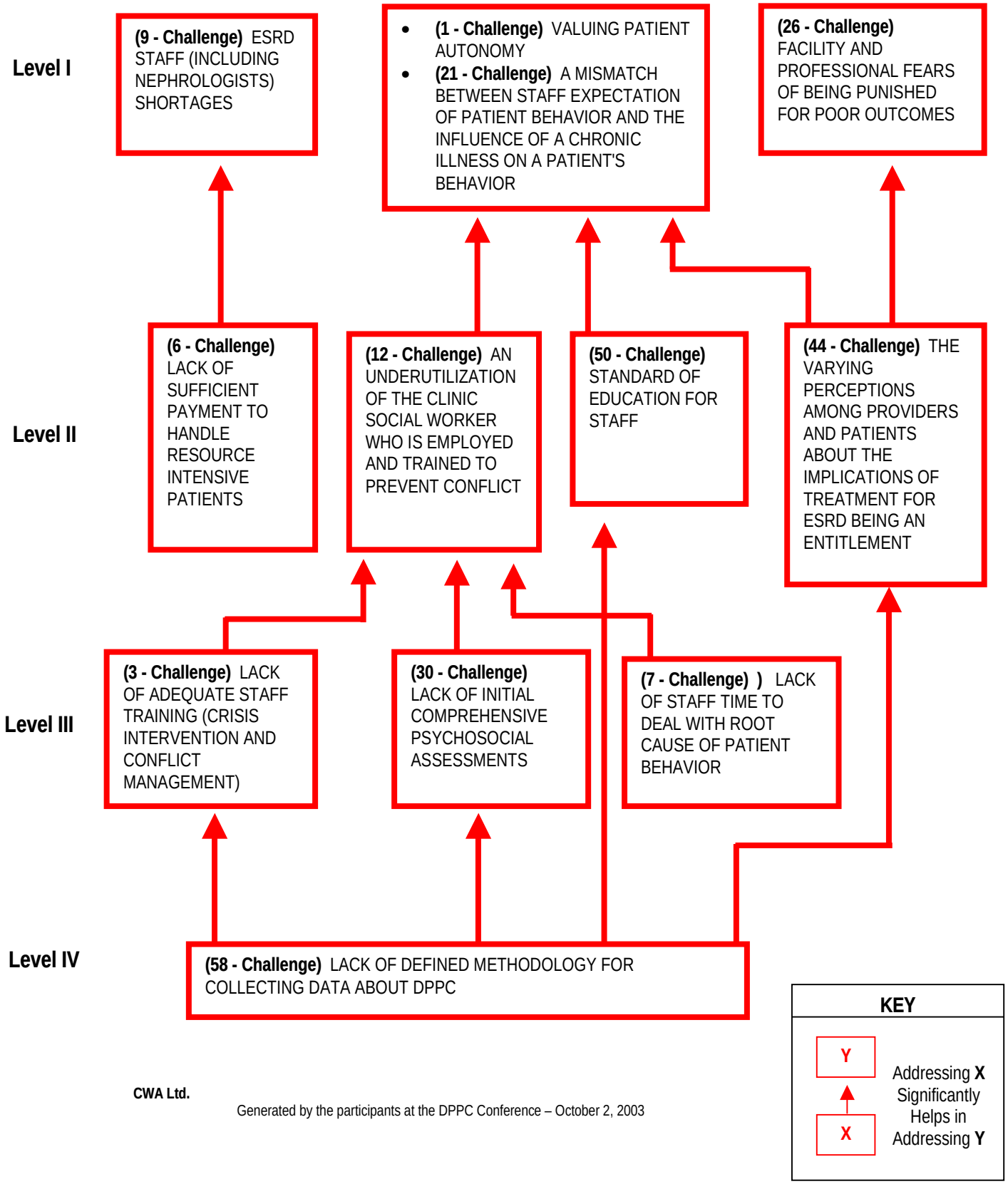
inadvertently exacerbate the potential for conflict, as they may not be as expert at defusing potentially explosive encounters, interviewees said. If situations blow out of control, dialysis units – faced with monetary constraints – may find it easier to dismiss problem patients rather than work through their problems. All these factors combine to set the stage for conflict, respondents said. While at first glance, the situation may seem not capable of resolution, the interviewees all agreed that were the dialysis community to come together to address these issues, they might well arrive at some solutions.

In the first stage of the conference, participants described and clarified sixty-seven anticipated challenges. The participants identified the twelve challenges they considered to be the most important. Through a robust investigation of influences among the challenges, decided by more than seventy strong majority votes, four challenges were identified as the most influential drivers appearing at the deepest levels of the tree-like pattern of Figure 1 (see page 4 and page 20). These challenges are:

- ***Lack of defined methodology for collecting data about DPPC;***
- ***Lack of adequate staff training (crisis intervention and conflict management);***
- ***Lack of initial comprehensive psychosocial assessments; and***
- ***Lack of staff time to deal with the root cause of patient behavior.***

Three features of this analysis stood out. First of all, although the conference's focus was on resolving the issues of conflict in dialysis facilities, the clarifications and discussions about one of these four most influential challenges focused on the inability *to collect enough information about the conflict we are trying to describe in order to study it better*. Secondly, two of the most influential drivers focused on the lack of staff time and training to deal with the root cause of patient behavior and to practice conflict management. The lack of understanding of the root cause of patient behavior influences the capacity to utilize the clinic social workers, who are in principle trained in crisis intervention and conflict management. Furthermore, without such training it is difficult to identify those patients and interventions that will actually have a positive impact on valuing patient autonomy, i.e., the honoring and respecting patients by every member of the healthcare treatment team. Thirdly, the lack of initial assessments of cognitive ability, personality coping, psychological disorder, etc. greatly inhibits the capacity to fully utilize the clinic social worker, who is employed and trained to prevent conflict.

Figure 1: Tree of Influence:
Amended Influence Pattern of Challenges for Addressing the DPPC Situation



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Generated by the participants at the DPPC Conference – October 2, 2003

In the second stage of the conference the participants generated and clarified more than forty proposed actions with emphasis on the four most influential challenges, displayed at the roots of the Tree of Influence shown in Figure 1 (see previous page).

The fifteen most important actions are shown in Table 4. It is interesting to note that in Table 4 the four higher priority actions mentioned earlier received more than 40% of the total vote count, and the eight top priority actions received 70% of the count. These results indicate the convergence of priority judgments among the participants of the conference.

These actions were used in a follow-up DELPHI study, the intent of which was to identify specific activities and collaborative leadership roles among the conference participants and their organizations.

Table 4: Voting Results on Consensus Action Options for Improving the DPPC Situation (Individual Votes and Team Scenarios Votes)

Team Scenario	Individual Votes	Action Option:
All 5 Teams	**(11)**	**(6 - Action Option)** ADOPT THE SETTING OF A NATIONAL CURRICULUM / STANDARD OF EDUCATION FOR DIALYSIS TECHNICIANS **(Cluster #2).**
All 5 Teams	**(8)**	**(11 - Action Option)** INCREASE REIMBURSEMENT IN KEEPING WITH INFLATION FOR DIALYSIS SO THAT FINANCIALLY STRETCHED CORPORATIONS CAN IMPLEMENT EDUCATIONAL AND OTHER INITIATIVES FOR DPPC **(Cluster #5).**
All 5 Teams	**(10)**	**(19 - Action Option)** ADOPT COMPREHENSIVE REGULATIONS FOR THE PROCEDURES AND STANDARDS FOR LIMITING AND TERMINATING PATIENT SERVICES AT A FACILITY **(Cluster #9).**
All 5 Teams	**(8)**	**(34 - Action Option)** LEVERAGE DIALYSIS UNITS TO "MAKE" SOCIAL WORKERS DO WHAT THEY'RE SUPPOSED TO -- NOT BE CLERICAL WORKERS **(Cluster #10).**
4 Teams	**(8)**	**(2 - Action Option)** HAVE THE NETWORKS AND/OR NIH AND/OR USRDS PROVIDE / INVENT A DATA GATHERING TOOL TO AID DATA COLLECTION AND METHODOLOGY **(Cluster #1).**
4 Teams	**(3)**	**(14 - Action Option)** INCREASE AND COORDINATE FEDERAL QA & QI ACTIVITIES **(Cluster #10).**
4 Teams	**(8)**	**(16 - Action Option)** REQUIRE FACILITIES TO REPORT INVOLUNTARY DISCHARGES TO THE NETWORK **(Cluster #1).**
4 Teams	**(5)**	**(22 - Action Option)** DEVELOP A TASK FORCE TO WORK ON THE DPPC RESEARCH PLAN AND ENUMERATE THE VARIABLES OF INTEREST AND THE ISSUES TO BE STUDIED **(Cluster #1).**
3 Teams	**(4)**	**(3 - Action Option)** CLARIFY AND CODIFY THE RIGHTS AND OBLIGATIONS OF PROVIDERS AND PATIENTS WHO OPERATE WITHIN AN ENTITLEMENT SYSTEM **(Cluster #3).**
3 Teams	**(2)**	**(4 - Action Option)** UTILIZE THE NETWORK #17 WORKING GLOSSARY AS A STARTING TAXONOMY FOR DATA COLLECTION FOR DPPC **(Cluster #1).**
3 Teams	**(4)**	**(8 - Action Option)** DEVELOP AN ALGORITHM FOR DETERMINING THE LEVEL OF DISRUPTIVE PATIENTS **(Cluster #9).**
3 Teams	**(3)**	**(28 - Action Option)** MAKE A BUSINESS CASE FOR IMPLEMENTING THE OPTIONS WE SEE HERE TODAY IN ORDER TO ENGAGE CORPORATIONS AND STAND ALONE DIALYSIS UNITS IN IMPLEMENTING THESE CHANGES **(Cluster #5).**
3 Teams	**(3)**	**(40 - Action Option)** INCLUDE CONFLICT PROBLEMS IN ROUTINE QA & QI PROGRAMS **(Cluster #10).**
3 Teams	**(8)**	**(45 - Action Option)** DISSEMINATE THE FINDING AND RECOMMENDATIONS OF THIS WORKSHOP TO THE RENAL COMMUNITY **(Cluster #7).**
2 Teams	**(4)**	**(21 - Action Option)** DEVELOP A SIMPLE BROCHURE OUTLINING THE BASIC TENETS OF CRISIS INTERVENTION AND CONFLICT MANAGEMENT **(Cluster #6).**

Produced by the participants at the DPPC Conference – October 3, 2003

One important action focuses on the need of educational standards:

- *Adopt the setting of a national curriculum/standard of education for dialysis technicians.*

Two actions clearly relate to the need to build on federal oversight and the coordination of QA and QI activities:

- *Leverage dialysis units to "make" social workers do what they are supposed to – not be clerical workers; and*
- *Increase and coordinate Federal QA and QI activities.*

Three important actions address the need to invent a tool and methodology for gathering data:

- *Have the Networks and/or NIH and/or USRDS provide/invent a data gathering tool to aid data collection and methodology;*
- *Require facilities to report involuntary discharges to the Network; and*
- *Develop a task force to work on the DPPC research plan and enumerate the variables of interest and the issues to be studied.*

One important action deals with the increase in reimbursement to provide incentives for improvements in education of the staff:

- *Increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives.*

Finally, one important action addresses the issue of prevention/termination:

- *Adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility.*

In stage three, conducted via a follow-up DELPHI survey, conference participants were asked to confirm their commitment to collaborative leadership on the top fifteen of their recommended actions.

Twenty participants from the ESRD community have expressed their commitment to inter-organizational collaboration on selected actions in the launch of the next phase of this initiative.

Approximately fourteen of twenty respondents to the DELPHI have identified their interests to focus their effort on addressing these most widely endorsed, and important actions. This

feedback further supports the participant's directive that the highest priority should be accorded to:

- ***Adopt the setting of a national curriculum / standard of education for dialysis technicians.***
  A: Author amended statement to include encourage or adopt. There are existing standards that won't cost units anything.
  Q: Would you consider removing encourage?
  Author accepted
  Q: Do you mean uniform national standard?
  That would be great but I don't see that happening. A national standard would be great.
  Q: Would you add provide federal reimbursement?
  Amended to include national standard
  C: The term standard means the lowest allowable, not optimal or benchmark.
  Number 17 Clarification was merged with #6
  C: Standards and curriculum are different.
  Item #6 amended to include curriculum.

- ***Increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives for DPPC.***
  I know we've been talking a lot about an important issue, but it's also a narrow issue as far as corporate obligations. We're not just a dialysis provider, we're a healthcare provider. So all of the initiatives that come down from federal government have to be implemented by corporation. A good example of that is HIPAA. Most corporations spent half a million implementing HIPAA. All of the things we're talking about are going to cost money. Interviewed people before I came here, the message was very clear. We're stressed as far as we can. We would like money left over to try to do something about the disease. We're going to have to find a little more money somewhere for much more to be implemented.
  Q: Would you consider adding after increase reimbursement, in keeping with inflation? Because I would suggest that that's been the error since 1973.
  R: I think that would be fine.
  C. That's not necessarily a bad thing, to attract capital into the market, shareholders will need to have decent return. We have been sympathetic to increases to get composite rate above water., We have supported and encouraged development of – we believe we should be paying a fair rate for dialysis services that let you be innovative and put in education so you can get best outcomes. If you can help us improve patient care and reduce hospitalization, we'd be more than happy to share that money with you. But just giving more money every year is an easy way out. We need to be smarter and work harder.

- ***Adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility.***
  This is the 600-pound gorilla, are there any questions? The program has been in existence since 1972, when Nixon was president, my hair came down to my shoulders, and we were involved in land war in Asia. Some things never change. I mean, there are detailed regulations that the IRS has and government publications dealing with how much money I can deduct for using my car for business purposes. There is nothing regarding what can essentially be a life and death decision for 360,000 people under this program. There's a disconnect.
  Q: Fascinating and provocative. The question is whether or not for example in spinning this out, I'm not arguing pro or con. My question is does this overlap into becoming a civil rights issue.
  R: Rules are two-edged swords. They establish a minimum standard that you have to meet, but they also establish a cover that if you meet them, you might be presumed to be acting reasonably. It's easier for an industry to take the bull by the horns and attempt to control what happens because if you don't, it's going to be determined by courts and not by the industry.

Q: Do you mean terminating benefits to a patient or terminating payment to a dialysis facility? R: This is strictly about what happens to the patient, rather than consequences for a facility.

Q: So if a patient were to pull a gun in dialysis unit, that would be reason for Medicare program to stop paying benefits?

R: No.

C: There's a difference between terminating treatment and terminating benefits. We have no right to terminate benefits. So maybe you want to put terminating treatment at that facility.

- ***Leverage dialysis units to "make" social workers do what they're supposed to – not be clerical workers.***
  A: We have data from Network #5 and from my observations that Social Workers are the defacto clerical workers in dialysis units. Dialysis units should be made to hire sufficient clerical personal so SWs can do what they are hired to do. They are grossly misused.

The community of stakeholders should allocate their resources in accomplishing the four high priority action options selected by all five small teams.

It is also interesting to point out that the DELPHI panel identified as a major challenge confronting the Forum of ESRD Networks the ability of the community to follow-up vigorously in implementing the consensus action options. Thirteen respondents expressed an interest in playing a leadership role in the dissemination of the findings and recommendations of this conference to the renal community. It is recommended that the ESRD Networks explore web-based alternative technologies that can enhance the dissemination and communication of the National Consensus Conference by providing access to the DPPC findings throughout the entire ESRD community.

INTRODUCTION

During the past 20 years, the number of people with End Stage Renal Disease (ESRD) on dialysis has increased to about 350,000.[1] Many in the field sense that along with that has been a rise in tension between dialysis patients and providers. While difficult patients may be a small percentage of all patients with ESRD, they can command a disproportionate amount of the unit staff's time, many in the field say. In addition, not only do patients exhibiting challenging behaviors place their own health at risk, they also endanger the health of other patients and potentially the providers. Yet, the question remains how to respond when faced with such a patient. For some, the answer is discharging or dismissing the patient, but not all in the field find that a satisfactory solution. Stories abound of units that discharge patients for infractions as minor as verbal abuse. Others strive to address the underlying factors that lead to the patients' misbehavior in the first place. Given the wide variability in units' standards for discharge, interviewees repeatedly endorsed the notion of a project to address this problem sooner rather than later. With the number of patients on dialysis projected to double by 2010,[2] many feel the time is ripe to identify ways to reduce the potential for conflict and improve the work environment for professionals and the prognosis for patients. The findings from the conference that launched this project will constitute the subject of this report.

The findings in this report, and participant commitment to the consensus actions, complete Phase One of this initiative. These findings represent the voice of representatives of the ESRD community of stakeholders that participated in the conference. Their statements, clarifications, and dialogue are preserved in their original form in this report as documented and distributed during the conference.

Twenty-five participants, and twenty-one observers, representing doctors, nurses, social workers, technicians, administrators, regulators, and patients participated in the conference on October 2-3, 2003. The list of participants and observers and their organizations is presented in Appendix A. At this event, stakeholders explored the challenges that will be faced by any attempt to improve the DPPC conflict situation and chose specific actions to undertake in the near future.

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[1] 2002 Annual Report, National Kidney Foundation.

[2] Beth Baker. "Earlier Kidney Testing Urged," The Washington Post, Feb. 5, 2002, F1.

Pre-Conference Discussion Paper

A Discussion Paper, based on interviews with seventeen representative stakeholders and a limited literature review, was produced in preparation for the conference. This analysis revealed that the majority of professionals in the field perceive that the dialysis provider-patient relationship in many instances has grown problematic. While a number of factors help explain the change, those interviewed also expressed concern about the potential upshot of dialysis patient-provider conflict – an increase in the number of dismissed patients. Finally, respondents offered a range of proposals to improve the situation, including establishing better definitions for non-compliance to interventions to reduce tension and defuse situations before they spiral out of control.

As discussed earlier, the dialysis patient population in recent years has grown larger and more diverse, a change made possible by the widespread access to dialysis afforded by Medicare. In addition, dialysis patients – like many patients in general -- have grown increasingly savvy about their care and more willing to question professional authority. Although this phenomenon by no means is restricted to dialysis care, the reality exists that dialysis patients have greater and more regular contact with healthcare providers than those with most other conditions.

Equally dramatic changes have occurred on the provider side of the relationship. In many dialysis facilities today, medical technicians now do the job of the nurse of yesteryear. But unlike nurses, these caregivers often enter the unit with little training, both in how to perform the tasks at hand as well as interact with patients. Compounding the problem, they often must perform the same tasks in significantly less time, leaving them little space to foster the relationships with patients that their predecessors had. Nurses in the unit are also pressed for time, with much of their job consumed by paperwork. Social workers are no different. Some carry caseloads of almost 200 patients spread over a number of clinics, said one respondent familiar with the situation. Although the Council of Nephrology Social Workers recommends caseloads of 75,[3] social workers interviewed for this project said that few in the field actually enjoy such manageable caseloads.

With all these stressors, it's little wonder that the patient-provider relationship often deteriorates. The question remains, however, what actions should be considered sufficient for

[3] Council of Nephrology Social Workers. Position Statement on Social Work Staffing, 1998.

dismissal. No one disputes that outright violent behavior is a red flag, but some interviewed questioned how to handle milder forms of non-compliance – threats, verbal abuse, missing appointments, or failing to adhere to a doctor's recommendations. While research suggests that physical abuse constitutes a small percentage of the problem, it tops the list of most providers' concerns, in part because of the threat it poses to unit staff and in part because it represents the most egregious form of patient behavior. Still, it's worth noting that one study found that only 16 percent of 525 grievance or complaint calls stemmed from disruptive or abusive patients and only about 6 percent regarded patient discharge.[4] Another study found that only about .2 percent of about 200,000 dialysis patients were discharged. Physical harm played a role in only 7.9 percent, of these cases and physical threat a role in 22.3 percent.[5]

Such findings notwithstanding, interviewees proposed a series of solutions, many of which were reiterated at the Consensus Conference in St. Louis. Many of these proposals entailed better equipping staff– including technicians, social workers, and physicians – to mediate potential conflicts before they occur. Some interviewees saw an increased role for social workers or psychologists from the onset of dialysis care. Others believed that increasing standards for ground-level workers -- in other words, the technician – would also contribute. Still others proposed logistical measures to improve the relationship between patient and provider from the perspective of both individuals. While many in the dialysis field appear resigned to the fact that at least some conflict will arise in the patient-provider relationship, many also fear that the drastic step of discharge is now an easy fix for too many units and want to intervene before this measure of last resort becomes commonplace. For a more in-depth discussion of the analysis conducted prior to the conference, please consult the discussion paper in Appendix B.

[4] TransPacific Renal Network Special Project on "The Patients (and Staff) Who Try Our Patience."

[5] "Involuntary Patient Discharge Survey 2002. A Collaborative Network Project," March 27, 2003.

A Guide to Reading this Report

The narrative in this report consists of two interwoven parts, one briefly explaining the system methodology used during the conference (including graphics that are displayed as Exhibits), the other describing the findings of the conference (including products displayed as Tables & Figures). The methodology sections simply answer the question "how did the participants get from one set of findings to another?" It is not necessary to read the methodology sections in order to understand the findings.

At the end of the report there is a compendium of the participants' contributions that are referred to throughout the findings. We encourage you to use the narrative of the report primarily as a guide to interacting directly with the voices of the participants through the compendium in its tables and figures. For example, the first section on findings below suggests that the reader at least scan the diversity of opinions, presented in Appendix C, before continuing.

1) CHALLENGES

1.1) METHODOLOGY: DEFINING COMPLEX PROBLEMS THROUGH COLLABORATION

1.1.1) Background

The approach to Phase I of the Forum of ESRD Networks initiative to engage the ESRD stakeholders in improving the DPPC situation is based on a Collaborative Action Planning model that has been developed over the last five years for inter-organizational collaboration. The model uses a methodology with a long established track record of applications in the systems sciences, and has been extensively subjected to the peer-review literature of the systems community. CWA Ltd. has customized the model to the unique requirements of inter-organizational stakeholder engagement essential to the formation of collaborative leadership in complex situations.

For the sake of brevity, specific discussion on the basis of this model in systems science has not been included in this report (see Appendix H). The presentation of the methodology here is solely employed to tie the flow of the findings together for the reader.

1.1.2) The Challenge of Collaboration in Complex Situations

Any group of people, when trying to solve a complex problem, confronts three challenges that actually represent opportunities.

1. First, the problem often seems vast, unwieldy, bewildering. Individual people often find one aspect of the problem easy to understand, but to each person the entire problem is overwhelming. If all the individual understandings could be somehow joined together, real progress would occur.
2. Second, individual people – depending on their backgrounds and training – perceive the problem differently, and use different terms or language to describe their perceptions. Again, uniting these differing perspectives could be a real opportunity to improve everyone's understanding of the problem, but often groups do not allow individuals enough time to clarify their perspective so that others understand them sufficiently, cutting short the group learning that is so essential to solving complex problem situations.
3. Finally, while no one in the group comprehends the entire problem, the group as a whole possesses a collective understanding of the problem that would enable them to map out how different components of the problem are related to each other. The trick is to devise a method that facilitates a group tapping into this collective understanding and wisdom in a constructive, goal-oriented manner.

The conference used a facilitation methodology that addresses each of these challenges, striving to turn them into collective opportunities. The facilitation approach in this conference proceeds through four basic stages – the first three of which are conducted during the conference, the fourth completed in a follow-up DELPHI survey (see Exhibits 1 and 2).

Exhibit 1: The Stages of Collaborative Inquiry

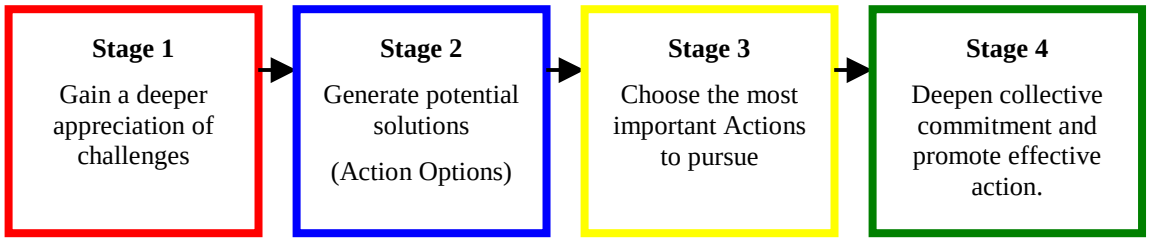


Exhibit 2: Directory of Findings from Each Stage

Stage 1 Findings	Stage 2 Findings	Stage 3 Findings	Stage 4 Findings
1) Discussion Paper in Appendix B **2) Clarification of Challenges, Table 1 in Appendix C** **3) Clusters of Challenges, Table 2, in Appendix D** **4) Influence Pattern of Challenges in Figure 1**	**1) Clarification of Action Options, Table 3 in Appendix E**	**1) Action Option Voting Results, Table 4** **2) Consensus Action Scenario, Figure 2**	**1) Commitments to Collaborative Leadership on Fifteen actions, the DELPHI Survey in Appendix G**

1.1.3) Stage One: Gain a Deeper Appreciation of Challenges

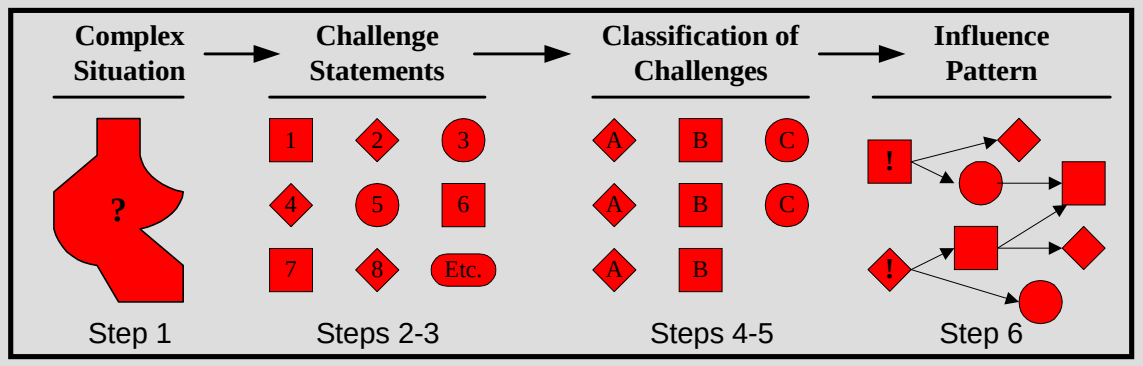
The first stage – gaining a better appreciation of component challenges – proceeded in six steps:

1. Before the conference, define a preliminary outline of the problem by interviewing knowledgeable people. These interviews are used as a means to provide participants at the conference with a rough sketch of the problem, to frame the question that starts the conference deliberations, and sensitize them to the diversity of opinion on the situation.
2. At the conference, describe the complex problem by articulating its component parts, with participants individually listing separate challenges that they think are important parts of the complex problem, in order to simplify matters.
3. Clarify individual perceptions about these challenges in order to promote group learning.
4. Present challenges within Affinity Clusters, i.e., categories of similar characteristics, and compile individual judgments (by voting) to further understand which challenges are of higher comparative importance.
5. Use group judgments (through strong majority votes) to understand how challenges are interrelated in terms of their influence upon one another.
6. Use this collective understanding to identify the most influential of the important challenges of the problem.

The products of these steps can also be viewed as a diagram. Exhibit 3 depicts how the group decomposed the complex situation into component challenges, worked to understand exactly what these challenges meant to the individual who authored them, and then deepened their

collective understanding of these challenges by seeing how they were interrelated. This results in the identification of challenges which are considered "deep drivers" of the situation (indicated by a ! in Exhibit 3) that influence the outcome of many other challenges. Resources committed to the deep drivers attain the highest overall leverage.

Exhibit 3: Products of Each Step in Stage One



We now turn to the findings of the conference during this first stage, namely gaining a deeper appreciation of the challenges to improving the DPPC situation.

1.2) FINDINGS: THE DEFINITION OF CHALLENGES

On the first day of the conference, stakeholders proposed and clarified responses to the following triggering question:

> ***"In light of the ideas presented in the Discussion Paper on the DPPC project, what are challenges (or problems) that the stakeholders of the ESRD community must address in resolving the issue of conflict in dialysis facilities?"***

Stakeholders described sixty-seven challenges and clarified their meanings during discussion with the entire group. The anticipated challenges and their clarifications appear as **Table 1 in Appendix C**. The challenges were grouped into clusters based on distinctions between challenges made by the stakeholders, during clarification.[*] Each participant chose five challenges, ranking them from 1 to 5 (most important to less important). Twelve challenges received at least four votes. These were used for the next step.

> *Note to the reader – if you were not a participant in the conference you should at least scan Appendix C in order to appreciate the diversity of opinions about the situation before continuing. You should determine whether your perspective on improving the DPPC situation is represented.*

[*] The clusters of challenges is presented in **Appendix D.** Cluster analysis was conducted by a member of the facilitation team, following a prescribed analysis method, and who relied solely on distinctions between challenges invoked by individual participants and interviewees. This was done primarily to enable the participants to vote for the challenges they considered most important in the context of a categorical view of challenges. Collaboration time on this step was minimized in favor of according more time to the investigation of influences. As such it carries the caveat that not too much should be read into this particular arrangement at this stage of the project. It is primarily a tool of inquiry rather than a product.

1.3) METHODOLOGY: DETERMINING INFLUENCES AMONG THE CHALLENGES

After describing a complex problem in terms of its component parts or challenges and perspectives on the challenges, people can better plan what to do if they take the time to understand how various challenges influence other challenges. Often, through this disciplined inquiry, people are able to discover that a seemingly insignificant challenge in fact directly and indirectly affects our ability to address a wide range of other challenges; meanwhile, a challenge that initially looked to be critical in fact has little influence on any other parts of the overall problem. The facilitation method takes the group through this discovery process by focusing the group on the question: "If we surmount this challenge, will we be better able to surmount another challenge?" This question is asked repeatedly with pairs of challenges. The group collectively decides yes or no by voting, and slowly a pattern of influence emerges. A computer program helps to discern this pattern by taking the results of the voting and using some basic inference logic. (For example, if surmounting A helps us tackle B, and surmounting B helps us tackle C, then surmounting A helps us tackle C and the question "does A influence C" does not have to be posed to the group). This saved the group two thirds of the time to complete this step in a robust fashion as compared to not having such support.

Those challenges that influence many other components of the problem can be thought of as having a lot of **LEVERAGE**, in that if we surmount these challenges, we are significantly better off in meeting lots of other challenges.

The entire group explored the influences among the twelve most important challenges resulting in the influence pattern represented in Figure 1 of the participant's workbooks and also appears as **Figure 1** (see page 20) of this report.

1.4) FINDINGS: THE PATTERN OF INFLUENCE AMONG THE CHALLENGES

Participants were asked relational questions that followed the following format:

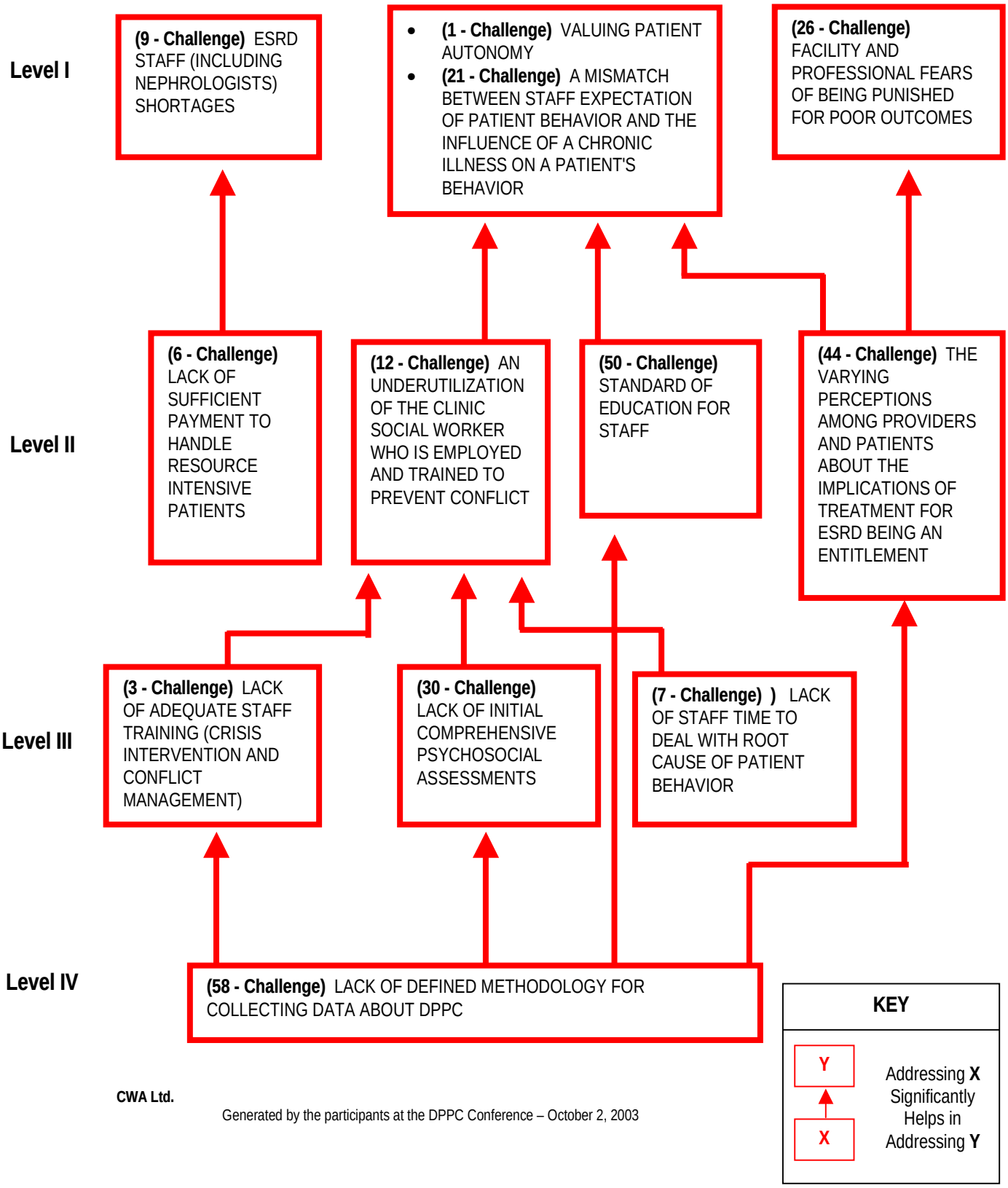
> "Suppose the community of stakeholders is able to make progress in addressing:
>
> **(Challenge X)**
>
> will this help significantly in addressing:
>
> **(Challenge Y)**
>
> in the context of designing an action plan for improving the DPPC situation?"

Based on a strong majority opinion of participant judgments about the interdependence between pairs of challenges, and the assistance of systems analysis software, an Influence Pattern was generated and is depicted in **Figure 1: Tree of Influence: Amended Influence Pattern of Challenges for Improving the DPPC Situation** (see next page). Arrows show cases where meeting one challenge will help significantly in meeting another challenge. This diagram represents the compilation of a strong consensus. It was generated by the assertions of at least eighteen of the twenty-six participants for each of the seventy-five relational questions. Unanimous opinions grew in frequency as the inquiry progressed.

Addressing challenges that appear lower in the Influence Tree have more wide-ranging effects than addressing ones that are higher, and thus the deeper challenges are the ones to tackle preferentially. Challenges that are lower in the influence pattern count as "more deeply leveraging" than higher ones, and this terminology will be used below.

The interpretation of the Influence Tree starts with the challenges at the top of the tree, and ends with those challenges that are located at the bottom level of the tree, and as a consequence have the most leverage on other challenges. Occasionally a challenge and its clarification are printed along with the discussion. Note that the statement of challenges and their clarifications are printed in *italic type* to emphasize that these words are quoted or paraphrased from the stakeholders' comments.

Figure 1: Tree of Influence:
Amended Influence Pattern of Challenges for Addressing the DPPC Situation



CWA Ltd.

Generated by the participants at the DPPC Conference – October 2, 2003

1.4.1) Interpretation of the Influence Tree

The directional arrow in Figure 1 indicates the propagation of enhancement from the root of the tree along the branches. Those challenges that are positioned at the root of the tree, i.e. Level IV, are more influential in terms of enhancement than those at higher levels. More specifically, **Challenge #58:** ***Lack of defined methodology for collecting data about DPPC,*** located at Level IV, enhances the capacity to meet all other challenges except for the two challenges that appear at Level II and Level I, namely challenges #6 and #9. These two challenges are in a track by themselves indicating that if the community of stakeholders were able to increase the payments for handling resource-intensive patients (Challenge #36), the ESRD staff shortages (Challenge #9) will be ameliorated.

It is also interesting to observe that Challenge #9, located at Level I, received 10 votes in terms of individual voting on relative importance by the conference participants. It turns out, however, that Challenge #9, although it is very important, is not influential at all since it is located at Level I of Figure 1. On the other hand, the most influential challenge, namely Challenge #58, appearing at the root of the tree (Level IV), received only 5 votes from participants. This observation of the distinction between importance and influence is a recurring phenomenon in the application of this particular systems methodology, and it has been referred in the systems sciences literature as the "Erroneous Priorities Law." The Law states that in complex situations, such as the DPPC, the true effective priorities are at the bottom of the tree of influence and not at the top, although importance voting accumulates at the top of the tree. In many instances in the healthcare arena, the priorities based on importance voting are implemented by the stakeholders leading to ineffective plans of action.

Another observation, regarding the interpretation of Figure 1, is that at Level I two challenges are located inside a box with bullets in front of them, namely Challenge #1 and Challenge #21. These two challenges are in a cycle of mutual influence, meaning that Challenge #1 influences strongly Challenge #21, and vice versa. The interpretation is that the valuing of the patient autonomy (Challenge #1) will be enhanced if the mismatch between the staff expectation of the behavior from chronic illness patients is met (Challenge #21), and vice versa.

In order to make progress in meeting the complex cycle of challenges #1 and #21 located in Level I, the community has to work on meeting the challenges that influence this cycle appearing at Level II, which are challenges #12, #50, and #44. These three challenges address critical issues such as the underutilization of the clinic social workers (Challenge #12), the standards of education for the clinic staff (Challenge #50), and the varying perceptions among providers and

patients about the implications of treatment for ESRD given that it is an entitlement (Challenge #44). Looking at Figure 1 one can observe that challenges #44 and #50 will be directly enhanced in terms of addressing them if the stakeholders were able to define a methodology for collecting data about DPPC (Challenge #58 at the root of the tree, which is connected directly by arrows to challenges #44 and #50).

Finally, the four challenges that exert strong influences in terms of the capacity of the community of stakeholders to meet other very important challenges in the tree of enhancement are:

Level III:

(Challenge-3): ***Lack of adequate staff training (crisis intervention and conflict management).***

Clarification:

We were talking about crisis intervention and conflict resolution, primarily to increase training for floor staff but provide that training to all people who work in the dialysis center.

(Challenge-30): ***Lack of initial comprehensive psychosocial assessments.***

Clarification:

A: This means everyone should have assessments that include assessment of cognitive ability, personality coping, psychological disorder, etc. I don't think everyone views it this way across facilities.

Q: Would this be a lack of comprehensive assessment?

R: Some do it, some don't.

Statement was amended.

(Challenge-7): ***Lack of staff time to deal with root cause of patient behavior.***

Clarification:

We were talking about, primarily due to the workload, the lack of time staff members have now just to talk with their patients, to find out what other underlying causes might be present contributing to that behavior. This lack of time is often viewed as an excuse by the patient, although it is truly a reality and often times that will result in conflict all by itself.

Level IV:

(Challenge-58): ***Lack of defined methodology for collecting data about DPPC.***

Clarification:

A: This refers to the ability to collect enough information about the conflict we are trying to describe in order to study it better.

The above four challenges are the deep drivers of the DPPC situation and need to be addressed preferentially in designing a collaborative action plan. This is the focus of the next section of this report.

2) ACTIONS

2.1) METHODOLOGY: DESIGNING ALTERNATIVE ACTION SCENARIOS

2.1.1) Stage Two and Three: Gain a Better Appreciation of Possible Actions

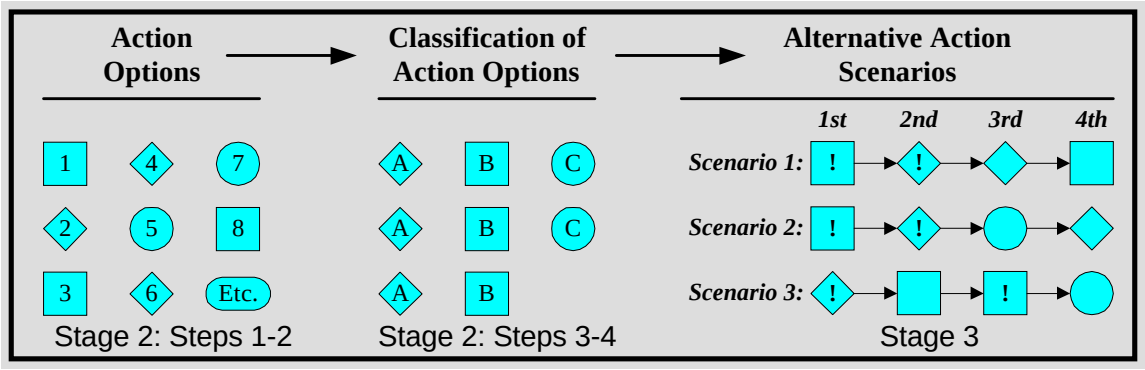
Having gained a deeper appreciation of the challenges as articulated by different individuals, and their interdependencies, the group next moves on to consider what can be done to surmount these challenges. The second stage proceeds in four steps:

1. Envision parts of the solution to the overall problem, with participants individually listing separate potential action options that address specific challenges.
2. Clarify individual perceptions about each action option, in order to promote group learning.
3. Cluster action options based on their similarity and compile individual judgments (by voting) to further understand which action options are of higher comparative importance.
4. Use this collective understanding to identify the most important action options.

In Stage 3 the teams construct alternative action scenarios. The teams achieve a working consensus on which actions to include in each team's proposed scenario and present it to the group.

Again, a diagram is helpful in seeing how the group moves from listing a wide variety of potential action options, to deepening their understanding of how these possible actions are similar to and different from each other, and finally choosing the most important action options and assembling them into alternative action scenarios, as graphically shown in Exhibit 4.

Exhibit 4: Displaying the Products of the Steps of Stage Two and Three



Different groups will devise alternative scenarios. Some groups will prioritize those action options that address very influential actions (designated by a ! in the diagram) as the first steps to be taken, whereas other groups might delay taking these actions until later. Having the groups

explain their reasoning underlying their scenario provides another opportunity for group learning and advances the group towards making the wisest choices of what actions to pursue and how.

We now turn to the findings of the conference regarding potential solutions to the complex problem of improving the DPPC situation.

2.2) FINDINGS: THE ACTION OPTIONS

On the second day of the conference, the stakeholders proposed and clarified ways to improve the DPPC situation. The stakeholders were divided into five groups. Each group then proposed action options in response to the following triggering question:

> ***"What are action options which, if adopted and implemented by the community of stakeholders, will help in addressing the system of challenges?"***

Participants generated and clarified forty-seven action options, which appears as **Table 3 in Appendix E**.

> *Note to the reader – if you were not a participant in the conference you should at least scan Appendix E in order to appreciate the variety of options in addressing the situation before continuing.*

The conference participants grouped similar action options together in "clusters," and drew distinctions amongst them by responding to questions according to the following format:

> "In the context of designing an action plan for improving the DPPC situation, does:
> (Action Option X)
> have significant characteristics in common with
> (Action Option Y)?"

The resulting clusters form the basis for the categorical view of action options, which was provided to the conference participants. This pattern was also displayed on the walls of the facilitation room. Participants were engaged in developing names that would characterize the overall intent of each cluster. In the context of this categorical view of stakeholder intentions, participants then voted for the action options they judged to be most important.

Teams of stakeholders were asked to consider how they would combine action options to improve the DPPC situation. They presented selections as "scenarios" to the group, also explaining how their plan would meet specific challenges from Day One. Fourteen action options

received four or more votes from individuals. The action options selected by two or more of the five small teams of participants for inclusion in the alternative team scenario are shown in **Table 4: Voting Results on Consensus Action Options for Improving the DPPC Situation** (see next page). They are also presented in the context of the affinity clusters as **Figure 2: Consensus Action Scenario Based on Small Team Work** (see pages 27 to 29).

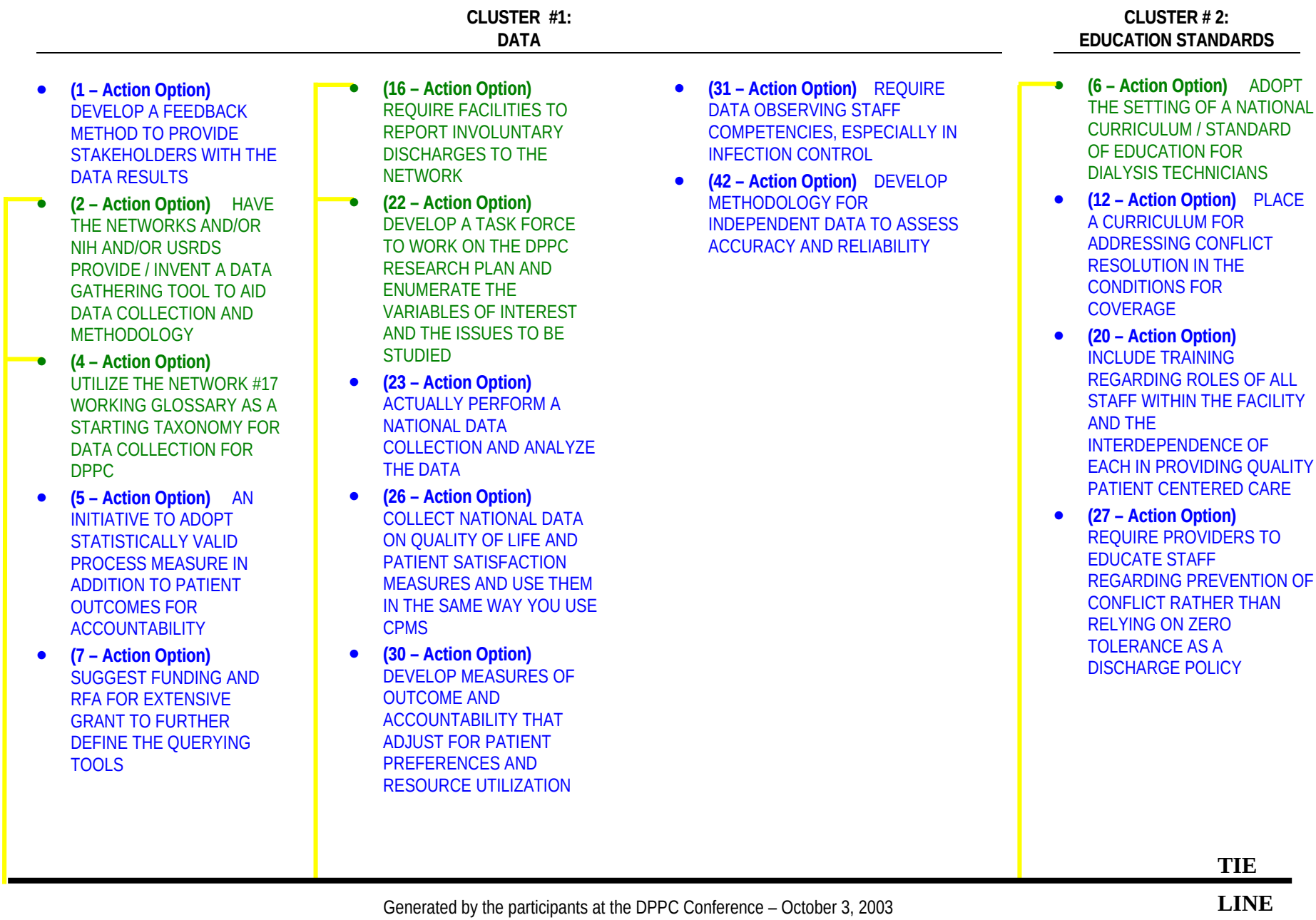
In this section, we discuss the consensus action options, their clarifications, and their importance as indicated by the day's voting. The discussion will concentrate on one cluster at a time, emphasizing the most preferred action options within the cluster. Where relevant, we will analyze the relationships to challenges that were identified previously (again, concentrating on the most highly-leveraging challenges).

Table 4: Voting Results on Consensus Action Options for Improving the DPPC Situation (Individual Votes and Team Scenarios Votes)

Team Scenario	Individual Votes	Action Option:
All 5 Teams	**(11)**	**(6 - Action Option)** ADOPT THE SETTING OF A NATIONAL CURRICULUM / STANDARD OF EDUCATION FOR DIALYSIS TECHNICIANS **(Cluster #2).**
All 5 Teams	**(8)**	**(11 - Action Option)** INCREASE REIMBURSEMENT IN KEEPING WITH INFLATION FOR DIALYSIS SO THAT FINANCIALLY STRETCHED CORPORATIONS CAN IMPLEMENT EDUCATIONAL AND OTHER INITIATIVES FOR DPPC **(Cluster #5).**
All 5 Teams	**(10)**	**(19 - Action Option)** ADOPT COMPREHENSIVE REGULATIONS FOR THE PROCEDURES AND STANDARDS FOR LIMITING AND TERMINATING PATIENT SERVICES AT A FACILITY **(Cluster #9).**
All 5 Teams	**(8)**	**(34 - Action Option)** LEVERAGE DIALYSIS UNITS TO "MAKE" SOCIAL WORKERS DO WHAT THEY'RE SUPPOSED TO -- NOT BE CLERICAL WORKERS **(Cluster #10).**
4 Teams	**(8)**	**(2 - Action Option)** HAVE THE NETWORKS AND/OR NIH AND/OR USRDS PROVIDE / INVENT A DATA GATHERING TOOL TO AID DATA COLLECTION AND METHODOLOGY **(Cluster #1).**
4 Teams	**(3)**	**(14 - Action Option)** INCREASE AND COORDINATE FEDERAL QA & QI ACTIVITIES **(Cluster #10).**
4 Teams	**(8)**	**(16 - Action Option)** REQUIRE FACILITIES TO REPORT INVOLUNTARY DISCHARGES TO THE NETWORK **(Cluster #1).**
4 Teams	**(5)**	**(22 - Action Option)** DEVELOP A TASK FORCE TO WORK ON THE DPPC RESEARCH PLAN AND ENUMERATE THE VARIABLES OF INTEREST AND THE ISSUES TO BE STUDIED **(Cluster #1).**
3 Teams	**(4)**	**(3 - Action Option)** CLARIFY AND CODIFY THE RIGHTS AND OBLIGATIONS OF PROVIDERS AND PATIENTS WHO OPERATE WITHIN AN ENTITLEMENT SYSTEM **(Cluster #3).**
3 Teams	**(2)**	**(4 - Action Option)** UTILIZE THE NETWORK #17 WORKING GLOSSARY AS A STARTING TAXONOMY FOR DATA COLLECTION FOR DPPC **(Cluster #1).**
3 Teams	**(4)**	**(8 - Action Option)** DEVELOP AN ALGORITHM FOR DETERMINING THE LEVEL OF DISRUPTIVE PATIENTS **(Cluster #9).**
3 Teams	**(3)**	**(28 - Action Option)** MAKE A BUSINESS CASE FOR IMPLEMENTING THE OPTIONS WE SEE HERE TODAY IN ORDER TO ENGAGE CORPORATIONS AND STAND ALONE DIALYSIS UNITS IN IMPLEMENTING THESE CHANGES **(Cluster #5).**
3 Teams	**(3)**	**(40 - Action Option)** INCLUDE CONFLICT PROBLEMS IN ROUTINE QA & QI PROGRAMS **(Cluster #10).**
3 Teams	**(8)**	**(45 - Action Option)** DISSEMINATE THE FINDING AND RECOMMENDATIONS OF THIS WORKSHOP TO THE RENAL COMMUNITY **(Cluster #7).**
2 Teams	**(4)**	**(21 - Action Option)** DEVELOP A SIMPLE BROCHURE OUTLINING THE BASIC TENETS OF CRISIS INTERVENTION AND CONFLICT MANAGEMENT **(Cluster #6).**

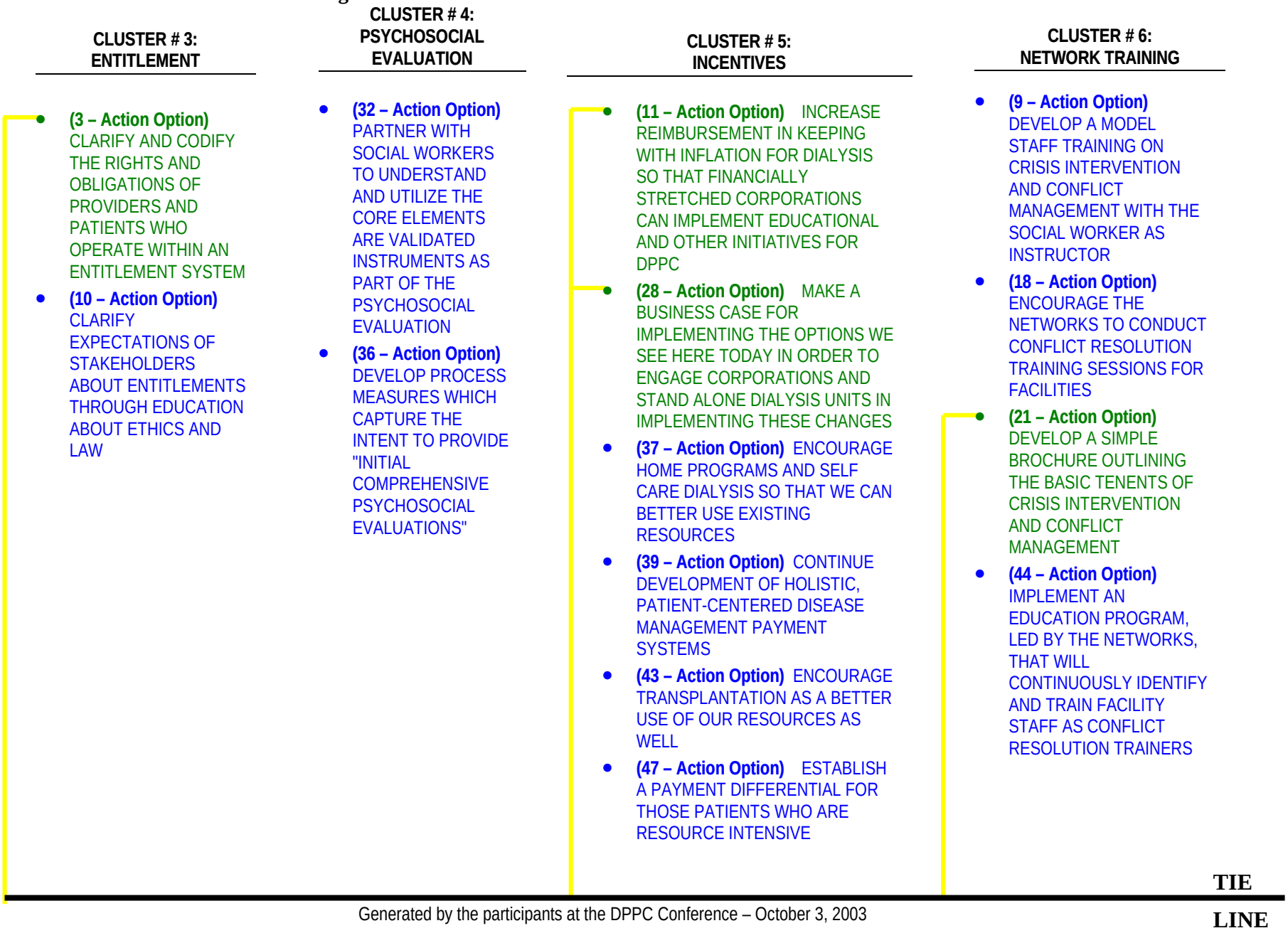
Produced by the participants at the DPPC Conference – October 3, 2003

Figure 2: Consensus Action Scenario Based on Small Team Work



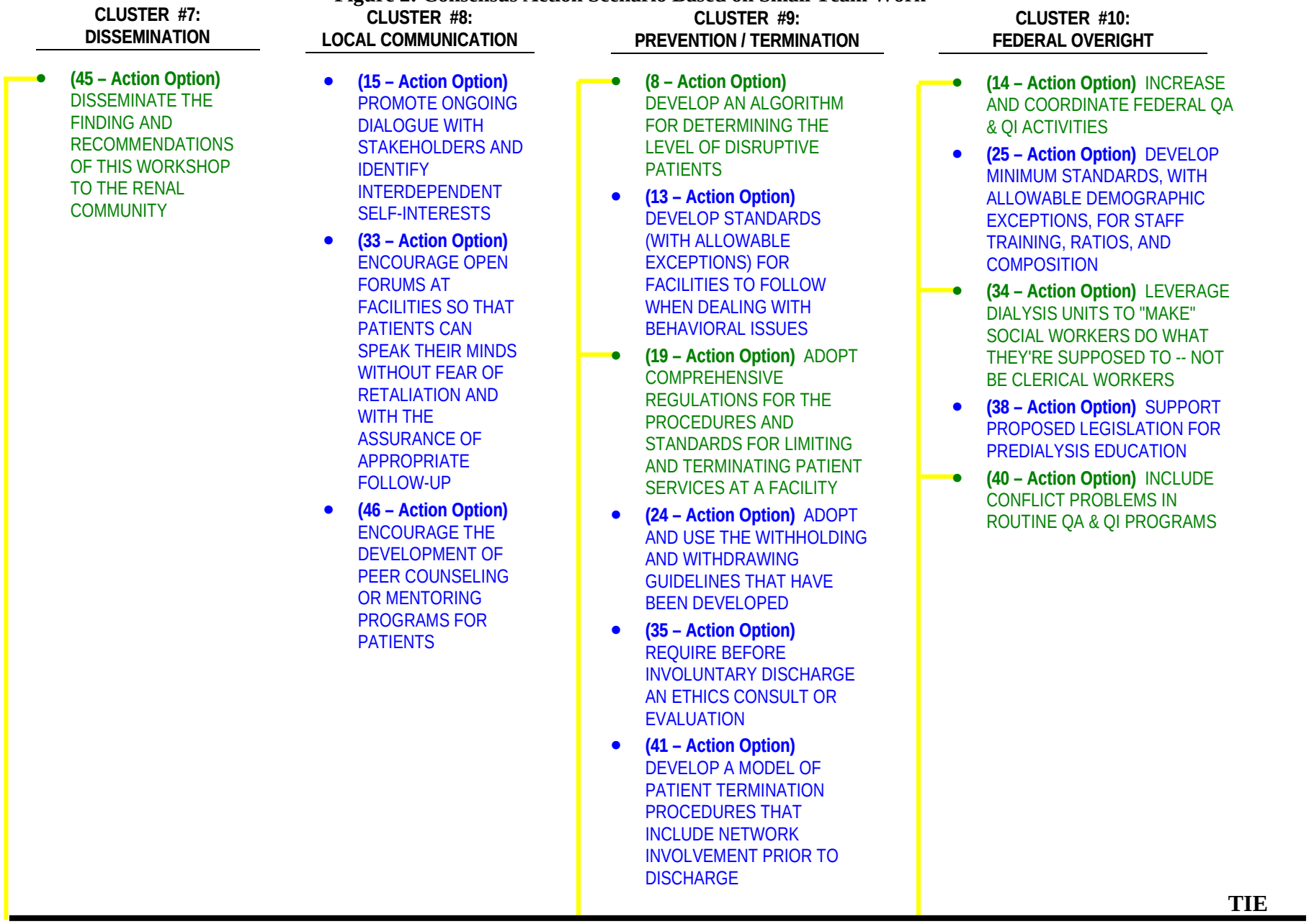
Generated by the participants at the DPPC Conference – October 3, 2003

Figure 2: Consensus Action Scenario Based on Small Team Work



Generated by the participants at the DPPC Conference – October 3, 2003

Figure 2: Consensus Action Scenario Based on Small Team Work



Generated by the participants at the DPPC Conference – October 3, 2003

2.2.1) Cluster 1: Data

This cluster contains the largest number of proposed action options, i.e., 12 action options out of a total of 47, which is approximately one fourth. All of these proposals are addressing the deep rooted challenge of the Influence Tree pattern discussed earlier, namely Challenge #58. It is interesting to observe that the participants of the conference recognized the high priority influence of Challenge #58, and as a result selected four actions options from this particular cluster for the recommended consensus action scenario shown in Figure 2 (see pages 27-29). These four action options are:

Action Option 2: ***Have the Networks and/or NIH and/or USRDS provide / invent a data gathering tool to aid data collection and methodology*****.**

Clarification:

A: Are there any questions about this?

Q: Do you think the networks can do this?

R: Usually the work flows from NIH to the network.

Q: Do you need to put "and or" in the statement?

Statement was amended

Q: There is a current program called Client Performance Measures project that correlates databases. Is what you are proposing in addition to that?

R: Yes. This is a separate data-gathering project that would clarify and define the issue.

Q: Does the "and or" go between networks and NIH?

R: Yes.

C: In the core data set we will be working on this. CPS are population and these are specific. The data will be reported back to the networks. This will be brought into the data issue. Don't know if we want to bring both into this. We want to get this done quickly.

Individual votes: 8. Scenarios: 4 teams

Action Option 4: ***Utilize the Network #17 working glossary as a starting taxonomy for data collection for DPPC.***

Clarification:

A: This work that network 17 and 18 did was funded by CMS and is good foundation for this (see info in notebook). Before defining methodology we need taxonomy to describe the situation. Since work has been done, this would jumpstart what we are doing.

Q: Could you use this as a start for a working document?

R: Yes.

C: These are nice descriptive glossaries but don't replace formal psychiatric diagnosis. You could use this descriptively but need formal documents. In the work done in 11 and 14 the survey indicated a lot of problems using psychiatric terms. Fear of labeling patients by someone who is not qualified to do this.

Not saying you can't proceed this way, there are real pitfalls to doing this you may won't someone qualified. Regarding adequate treatment if you don't do that you cut off from Mental Health services… We're not talking about diagnosis.

Q: I agree. Psychiatric evaluations when a situation happen in the unit, people are looking for behaviors, psychiatric evaluations come later. If patient is abusive they are forget why the behavior is there.

Q: Can we offer changes to statement?

Include suggestion about DSM 4 in, DSM 4 diagnosis,

The only thing network 35 did that I take exception to is the term nonconformity connotes molding of patients in preconceived way were non-adherence.

Statement amended

If we go beyond characterizing actions and labeling patients it becomes an ADA issue. Don't want networks getting into this. Cautioning against this.

I think the glossary is helpful this would be a nice way to get idea of what's going on. Need a clinical psychiatrist to make diagnosis.

Individual votes: 2. Scenarios: 3 teams

Action Option 16: ***Require facilities to report involuntary discharges to the Network.***

Clarification:

A: The data that networks collect does not currently include lost or follow up. There is no mechanism to gather involuntary discharges. There should be a mechanism to include this on an individual basis. When they occur have a phone call.

C: We have a workgroup in the network working on this. We are developing a broad definition for but it does not include a call to the PSD.

Q: Would you add to your statement, wording that gets to networks not just reporting but involvement and reporting to networks so they are involved in process?

A: For clarity, I will leave as is.

Individual votes: 8. Scenarios: 4 teams

Action Option 22: ***Develop a task force to work on the DPPC research plan and enumerate the variables of interest and the issues to be studied.***

Clarification:

A: This is one of the next steps to help put together this plan.

Individual votes: 5. Scenarios: 4 teams

With the exception of Action Option #4, which was selected only by 3 teams in their scenarios, the other three action options received 4 team scenario votes. It is also interesting to notice that Action Option #4 received only 2 individual votes, so it was not perceived as being of high relative importance during the individual voting. However, at the plenary discussion at the end of the conference it was decided by a majority vote to include this action option in the consensus scenario. This phenomenon is not unusual in the construction of scenarios portion of this methodology. It is attributed to the evolution of learning that occurs among the participants during the deliberations of the small teams.

2.2.2) Cluster 2: Education Standards

Only one action option was selected for inclusion in the consensus action scenario from cluster 2, namely:

Action Option 6: ***Adopt the setting of a national curriculum / standard of education for dialysis technicians.***

Clarification:

A: Author amended statement to include encourage or adopt. There are existing standards that won't cost units anything.

Q: Would you consider removing encourage?

Author accepted

Q: Do you mean uniform national standard?

That would be great but I don't see that happening. A national standard would be great.

Q: Would you add provide federal reimbursement?

Amended to include national standard

C: The term standard means the lowest allowable, not optimal or benchmark.

Number 17 Clarification was merged with #6

C: Standards and curriculum are different.

Item #6 amended to include curriculum.

Individual votes: 11. Scenarios: 5 teams

This action option received the highest number of individual votes on relative importance. Also all 5 teams included it in their scenario. It is the action option that will clearly impact Challenge #3 in Figure 1, addressing the concern about lack of staff training in crisis intervention and conflict management. This challenge was identified as a deep driver of the DPPC situation. By entering the Influence Tree at Level III, its impact will propagate upwards and enhance the capacity of the community to address other challenges, such as Challenges #12, #1, and #21 (see Figure 1, page 20).

2.2.3) Cluster 3: Entitlements

Only one action option was selected for inclusion in the consensus action scenario from Cluster 3, namely:

Action Option 3: ***Clarify and codify the rights and obligations of providers and patients who operate within an entitlement system.***

Clarification:

I think there was a fair amount of discussion yesterday about what exactly an entitlement program is. I think we are one and this is simply a suggestion for all of us who operate in system, including patients, to understand what this means, legal or otherwise.

Q: By codify, do you mean new legislation, conditions of coverage, federal standards…

R: To me, it means to lay out in clear language, not interpretable for the region or state. I'm just asking in layman's language what does this mean.

C: Now you know clearness and codify are two mutually exclusive things.

Q: Do you mean like a provider and patient's bill of rights?

R: Not only rights and responsibilities, but a very brief and concise statement of what the program is. This is ESRD, this is what it means to patients and providers. More than a bill of rights, it would have… I don't know exactly what I mean. It would not be subject to local interpretation. This is a federal program.

Q: So you're talking about federal interpretation of current entitlement laws?

R: I think since I and everyone else here pay taxes for it, yeah.

Q: A simple English interpretation?

R: Yeah.

Individual votes: 4. Scenarios: 3 teams

This action option clearly impacts **Challenge #44:** ***The varying perceptions among providers and patients about the implications of treatment for ESRD being an entitlement***, which is located at Level II of Figure 1. Implementation of this action option will contribute significantly in addressing these varying perceptions. It will also impact positively three other important challenges that are located at Level I of Figure 1, namely challenges #1, #21, and #26. By focusing on **Challenge #26**: ***Facility and professional fears of being punished for poor outcomes***, it is clear that the implementation of the action option which clarifies the rights and obligations of providers and patients will help in terms of ameliorating these fears. Such clarification of rights and obligations was also perceived by the interviewees as a significant factor for the reduction of the level of conflict in dialysis facilities.

2.2.4) Cluster 5: Incentives

Two action options were selected for inclusion in the consensus action scenario. The first one is:

Action Option 11: ***Increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives for DPPC.***

Clarification:

> *I know we've been talking a lot about an important issue, but it's also a narrow issue as far as corporate obligations. We're not just a dialysis provider, we're a healthcare provider. So all of the initiatives that come down from federal government have to be implemented by corporation. A good example of that is HIPAA. Most corporations spent half a million implementing HIPAA. All of the things we're talking about are going to cost money. Interviewed people before I came here, the message was very clear. We're stressed as far as we can. We would like money left over to try to do something about the disease. We're going to have to find a little more money somewhere for much more to be implemented.*
>
> *Q: Would you consider adding after increase reimbursement, in keeping with inflation? Because I would suggest that that's been the error since 1973.*
>
> *R: I think that would be fine.*
>
> *C. That's not necessarily a bad thing, to attract capital into the market, shareholders will need to have decent return. We have been sympathetic to increases to get composite rate above water., We have supported and encouraged development of – we believe we should be paying a fair rate for dialysis services that let you be innovative and put in education so you can get best outcomes. If you can help us improve patient care and reduce hospitalization, we'd be more than happy to share that money with you. But just giving more money every year is an easy way out. We need to be smarter and work harder.*

Individual votes: 8. Scenarios: 5 teams

This idea garnered impressive support, receiving a comparatively large number of individual votes and being included in all team scenarios. It has an obvious attraction: If we could increase

reimbursement in keeping with inflation it will be much easier to implement educational and other initiatives.

The second action option is:

Action Option 28: ***Make a business case for implementing the options we see here today in order to engage corporations and stand alone dialysis units in implementing these changes.***

Clarification:

A: We need to go through these we should develop a cost benefit analysis to see if these proposals will lead to a cost savings, if it will be costly and will be a long-term benefit. We should determine if we solve this as a business proposal.

Q: Would this include analysis of results of data collection that we talked about?

R: Whatever projects or solutions we generate today we should include in that a business analysis.

Individual votes: 3. Scenarios: 3 teams

Although only three participants voted individually for this action option and only three teams included it in their team scenario, it was decided during the plenary discussion that it merited inclusion in the consensus scenario.

2.2.5) Cluster 6: Network Training

One action option was selected from Cluster 6 during the plenary discussion, even though it received only 4 individual votes and 2 team votes. This is:

Action Option 21: ***Develop a simple brochure outlining the basic tenets of crisis intervention and conflict management.***

Clarification:

With relatively little work, this group I think could develop a quick brochure. With relatively little work and some additional funding, this could be quickly distributed and put in the hands of clinical providers.

Individual votes: 4. Scenarios: 2 teams

2.2.6) Cluster 7: Dissemination

The only action option assigned to this cluster was included in the consensus action scenario on the basis of 8 individual votes and 3 team votes. This is:

Action Option 45: ***Disseminate the finding and recommendations of this workshop to the renal community.***

Clarification:

I just think the things that come from the conference, other people need to know about it, we need other people to weigh in really heavily.

C: Think properly structured, this might be something to submit to AJKD as a special article. Think the paradigms that are put forward here, should be distributed to the renal community and that should be done in a peer-reviewed journal.

R: Actually think of something other than just a journal article here and having other people weigh in.

Individual votes: 8. Scenarios: 3 teams

2.2.7) Cluster 9: Prevention/Termination

Two action options were selected from Cluster 9. These are:

Action Option 8: ***Develop an algorithm for determining the level of disruptive patients.***
Clarification:

A: Develop something that will help the staff determine what level of disruption it is, i.e. yelling, medium: yelling and profanities severe: striking out.

Individual votes: 4. Scenarios: 3 teams

Action Option 19: ***Adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility.***
Clarification:

This is the 600-pound gorilla, are there any questions? The program has been in existence since 1972, when Nixon was president, my hair came down to my shoulders, and we were involved in land war in Asia. Some things never change. I mean, there are detailed regulations that the IRS has and government publications dealing with how much money I can deduct for using my car for business purposes. There is nothing regarding what can essentially be a life and death decision for 360,000 people under this program. There's a disconnect.

Q: Fascinating and provocative. The question is whether or not for example in spinning this out, I'm not arguing pro or con. My question is does this overlap into becoming a civil rights issue?

R: Rules are two-edged swords. They establish a minimum standard that you have to meet, but they also establish a cover that if you meet them, you might be presumed to be acting reasonably. It's easier for an industry to take the bull by the horns and attempt to control what happens because if you don't, it's going to be determined by courts and not by the industry.

Q: Do you mean terminating benefits to a patient or terminating payment to a dialysis facility?
R: This is strictly about what happens to the patient, rather than consequences for a facility.

Q: So if a patient were to pull a gun in dialysis unit, that would be reason for Medicare program to stop paying benefits?

R: No.

C: There's a difference between terminating treatment and terminating benefits. We have no right to terminate benefits. So maybe you want to put terminating treatment at that facility.

Individual votes: 10. Scenarios: 5 teams

This last action options clearly received a significant number of individual votes and team scenario votes. As stated by the clarification by the author, the participants felt very strongly about the distinction between terminating treatment of a patient and terminating payment to a facility, and the legal and ethical implications of such action.

2.2.8) Cluster 10: Federal Oversight

Three out of a total of five action options in this cluster were included in the consensus action scenario. Two of the selected options deal with QA and QI activities, and the third deals

with the predicament of the social workers being utilized as clerical workers in the dialysis units. The three consensus action options are:

Action Option 14: ***Increase and coordinate federal QA & QI activities.***
Clarification:

A: The regulations are useless if they are not enforced. We have a resource in the ESRD networks to help facilities. We want them to help clinics, and independent providers involved. Many of them don't know how to do QI. They need additional resources to fix things before state surveyors come in. It is better to fix a problem before a problem. We don't want to shut them down. The ramifications are disturbing. We need to get the networks and state surveyors working together. This would be a better approach. Federal improvements take time.

C: One hazard in a uniform approach is that what we collect analyze.

R: Yes.

Q: All facilities say they have QA or QI but don't address these problems specifically. Do we want to add language that focuses on this particular problem?

R: No, this is just our oversight of the program in general.

Q: Can we add language that speaks to getting this problem included?

Group decided to propose new item 40.

Individual votes: 3. Scenarios: 4 teams

Action Option 34: ***Leverage dialysis units to "make" social workers do what they're supposed to -- not be clerical workers.***
Clarification:

A: We have data from Network #5 and from my observations that Social Workers are the defacto clerical workers in dialysis units. Dialysis units should be made to hire sufficient clerical personal so SWs can do what they are hired to do. They are grossly misused.

Individual votes: 8. Scenarios: 5 teams

Action Option 40: ***Include conflict problems in routine QA & QI programs.***
Clarification:

A: I don't think that facilities know to improve this in routine exam and processes. I want to see this addressed.

Individual votes: 3. Scenarios: 3 teams

Action Option #34 will clearly have a positive impact on addressing **Challenge #12:** ***An underutilization of the clinic social worker who is employed and trained to prevent conflict,*** which is located at Level II in Figure 1. By resolving the predicament of the role of the social worker in the clinic, the stakeholders will be able to have a very positive impact on the cycle involving two very important challenges, one of which is focusing on valuing patient autonomy (Challenge #1), and the other on the mismatch between staff expectation and patient behavior (Challenge #21), both of which are located at Level I of Figure 1. The challenge of "valuing patient autonomy" received 8 individual votes during the voting of relative importance among the 67 challenges that were proposed and clarified during the first day of the conference, indicating the importance attributed to this challenge by the participants.

3) CONSENSUS

3.1) METHODOLOGY: SCENARIO CONSTRUCTION

The participants were arranged in five small groups based on maximizing the diversity of perspectives within each group. The groups deliberated on selecting actions that they would include in a prospective Action Plan. The Clusters of action options they had developed in the large group (see Figure 2), during the previous step were provided as a working template. The groups were instructed to first consider the inclusion of each of the fourteen action options that had received at least four individual votes. They then moved on to consider the inclusion of action options that had not previously been accorded importance by more than four people. Four of these action options were included by at least two of the teams.

The groups were then coached in developing narrative descriptions of their plans. The groups presented their scenarios to the full set of participants. The groups typically employed a narrator, and one person using the wall displays of the structure of challenges and the Clusters of action options. The group's scenario narratives were tracked and videotaped by the facilitation team for further analysis.

3.2) FINDINGS: SMALL TEAM ACTION SCENARIOS

The Consensus Action Scenario was developed as a composite of small group work by five interdisciplinary teams, and appears in Figure 2. The summary of their selected actions appears in Table 4.

Fifteen actions were selected by two or more teams. The selected actions are graphically presented in Figure 2 by connecting them to the TIE LINE at the bottom of the Figure. This constitutes the Consensus Action Scenario as generated during the deliberations of the participants at the conference.

4) COMMITMENT TO COLLABORATIVE LEADERSHIP

The fifteen actions highlighted in section 3.2 and Table 4 were confirmed through a post-conference DELPHI Survey, as the actions to focus on for the Launch of Phase II of the initiative. The DELPHI Survey Cover Letter appears in Appendix F, and the responses appear in Appendix G.

Approximately fourteen of twenty respondents to the DELPHI have identified their interests to focus their effort on addressing these most widely endorsed, and important actions. This feedback further supports the participant's directive that the highest priority should be accorded to:

- ***Adopt the setting of a national curriculum / standard of education for dialysis technicians.***
  A: Author amended statement to include encourage or adopt. There are existing standards that won't cost units anything.
  Q: Would you consider removing encourage?
  Author accepted
  Q: Do you mean uniform national standard?
  That would be great but I don't see that happening. A national standard would be great.
  Q: Would you add provide federal reimbursement?
  Amended to include national standard
  C: The term standard means the lowest allowable, not optimal or benchmark.
  Number 17 Clarification was merged with #6
  C: Standards and curriculum are different.
  Item #6 amended to include curriculum.
- ***Increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives for DPPC.***
  I know we've been talking a lot about an important issue, but it's also a narrow issue as far as corporate obligations. We're not just a dialysis provider, we're a healthcare provider. So all of the initiatives that come down from federal government have to be implemented by corporation. A good example of that is HIPAA. Most corporations spent half a million implementing HIPAA. All of the things we're talking about are going to cost money. Interviewed people before I came here, the message was very clear. We're stressed as far as we can. We would like money left over to try to do something about the disease. We're going to have to find a little more money somewhere for much more to be implemented.
  Q: Would you consider adding after increase reimbursement, in keeping with inflation? Because I would suggest that that's been the error since 1973.
  R: I think that would be fine.
  C. That's not necessarily a bad thing, to attract capital into the market, shareholders will need to have decent return. We have been sympathetic to increases to get composite rate above water., We have supported and encouraged development of – we believe we should be paying a fair rate for dialysis services that let you be innovative and put in education so you can get best outcomes. If you can help us improve patient care and reduce hospitalization, we'd be more than happy to

share that money with you. But just giving more money every year is an easy way out. We need to be smarter and work harder.

- ***Adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility.***
  This is the 600-pound gorilla, are there any questions? The program has been in existence since 1972, when Nixon was president, my hair came down to my shoulders, and we were involved in land war in Asia. Some things never change. I mean, there are detailed regulations that the IRS has and government publications dealing with how much money I can deduct for using my car for business purposes. There is nothing regarding what can essentially be a life and death decision for 360,000 people under this program. There's a disconnect.

  Q: Fascinating and provocative. The question is whether or not for example in spinning this out, I'm not arguing pro or con. My question is does this overlap into becoming a civil rights issue.

  R: Rules are two-edged swords. They establish a minimum standard that you have to meet, but they also establish a cover that if you meet them, you might be presumed to be acting reasonably. It's easier for an industry to take the bull by the horns and attempt to control what happens because if you don't, it's going to be determined by courts and not by the industry.

  Q: Do you mean terminating benefits to a patient or terminating payment to a dialysis facility? R: This is strictly about what happens to the patient, rather than consequences for a facility.

  Q: So if a patient were to pull a gun in dialysis unit, that would be reason for Medicare program to stop paying benefits?

  R: No.

  C: There's a difference between terminating treatment and terminating benefits. We have no right to terminate benefits. So maybe you want to put terminating treatment at that facility.

- ***Leverage dialysis units to "make" social workers do what they're supposed to – not be clerical workers.***
  A: We have data from Network #5 and from my observations that Social Workers are the defacto clerical workers in dialysis units. Dialysis units should be made to hire sufficient clerical personal so SWs can do what they are hired to do. They are grossly misused.

The community of stakeholders should allocate their resources in accomplishing the four high priority action options selected by all five small teams.

It is also interesting to point out that the DELPHI panel identified as a major challenge confronting the Forum of ESRD Networks the ability of the community to follow-up vigorously in implementing the consensus action options. Thirteen respondents expressed an interest in playing a leadership role in the dissemination of the findings and recommendations of this conference to the renal community. It is recommended that ESRD Networks explore web-based alternative technologies that can enhance the dissemination and communication of the National Consensus Conference by providing access to the DPPC findings throughout the entire ESRD community.

APPENDICES

Appendix A: Participants & Observers

Appendix B: Discussion Paper

Appendix C: Clarification of Challenges

Appendix D: Challenge Clusters

Appendix E: Clarification of Action Options

Appendix F: DELPHI Survey Cover Letter

Appendix G: DELPHI Survey Responses

Appendix H: Bibliography Relevant to the Methodology

APPENDICES

APPENDIX A

Participants & Observers

Dialysis Patient-Provider Conflict:
Designing a Collaborative Action Plan with the ESRD Stakeholders
National Consensus Conference
October 2 – 3, 2003
Hilton St. Louis Airport

REVISED LIST OF PARTICIPANTS

Name	Organization	Contact Information
Karin Anderson-Barrett, Esq.....	Dialysis Clinic, Inc.	Legal Counsel Dialysis Clinic, Inc. 1633 Church Street, Suite 500 Nashville, TN 37203 Phone: (615) 342-0456 Fax: (615) 329-6705 Email: Karin.Barrett@dciinc.org
Brady Augustine, M.S	Centers for Medicare & Medicaid Services (CMS)	Senior Advisor to the Director Center for Medicare Management Centers for Medicare & Medicaid Services 7500 Security Boulevard Mail Stop C5-11-24 Baltimore, Maryland 21244-1850 Phone: (410) 786-5323 Email: baugustine@cms.hhs.gov
Debbie Benner, MA, RD, CSR	Council on Renal Nutrition (CRN) of the National Kidney Foundation	National Director Nutritional Services DaVita Inc. 16255 Laguna Canyon Road Irvine, CA 92618 Phone: (949) 453-1981 Fax: (949) 453-1982 Email: dbenner@davita.com
Elaine R. Colvin, RN, BSN, MEPD.....	American Nephrology Nurses' Association (ANNA)	Chairperson of ANNA's Ethics Committee W3275 STH 16 West Salem, WI 54669 Phone: (608) 775-6673 Fax: (608) 775-5941 Email: ercolvin@gundluth.org
Sandie Guerra Dean, MSW, LICSW	Fresenius Medical Care NA	Corporate Social Worker Fresenius Medical Care NA 95 Hayden Avenue Lexington, MA 02420 - 9192 Phone: (781) 402-4499, 800-662-1237 ext. 4499 Fax: (781) 402-9709 Email: sandie.dean@fmc-na.com

Linda Dickenson, BSN, CNN, CPHQ ..	National Nephrology Associates (NNA) (partial participant)	Director of Education National Nephrology Associates 230 Great Circle Road, Suite 218 Nashville, TN 37228 Phone: (615) 777-8046 Email: ldickenson@nnacorp.com
Cammie Dunnagan.....	Information Infrastructure Workgroup (subcommittee of the Forum Board of Directors)	Director of Information Systems Southeastern Kidney Council, Inc. 1000 St. Albans Drive Suite 270 Raleigh, NC 27609 Phone: (919) 855-0882 Fax: (919) 855-0753 Email: cdunnagan@nw6.esrd.net
Brenda Dyson	America Association of Kidney Patients (AAKP)	President America Association of Kidney Patients 3505 E. Frontage Road Suite 315 Tampa, FL 33607 Phone: (813) 636-8100 (800) 749-2257 (toll free) Fax: (813) 636-8122 Email: bdyson@nw8.esrd.net
Richard Feferman, Esq.	Attorney	Feferman & Warren 300 Central Avenue, S.W. Suite 200 East Albuquerque, NM 87102 Phone: (505) 243-7773 Fax: (505) 243-6663 Email: rfeferman@msn.com
Bonnie Freed, RN, MBA.....	Network Executive Directors	Executive Director ESRD Network 4, Inc. 40 24th Street Suite 410 Pittsburgh, PA 15222 Phone: (412) 325-2250 Fax: (412) 325-1811 Email: bfreed@nw4.esrd.net
Clifford Glynn, CHT	National Association for Nephrology Technicians/Technologists (NANT)	National Association for Nephrology Technicians/Technologists PO Box 2307 Dayton, OH 45401-2307 Phone: (937) 586-3705 (877) 607-6268 (toll free) Fax: (937) 586-3699 Email: Clifford.Glynn@kdpnw.kdp-baptist.louisville.edu And cdialyzer@msn.com

Richard S. Goldman, MD…….	The Forum of ESRD Networks	**Consensus Conference Co-Chair** 4522 Sunningdale NE Albuquerque, NM 87110 Phone: (505) 266-6566 Fax: (505) 266-2241 Email: DickG62697@aol.com
Kay. M. Hall, BSN, RN, CNN	Gambro Healthcare U.S.	Director Regulatory Affairs/Licensure and Certification Gambro Healthcare U.S. 5200 Virginia Way Brentwood, TN 37027 Phone: (615) 320-4513 Fax: (615) 320-4473 Email: Kay.Hall@us.gambro.com
Glenda Harbert, RN, CNN, CPHQ..	The Forum of ESRD Networks	**Consensus Conference Co-Chair** Executive Director ESRD Network of Texas, Inc. 14114 Dallas Pkwy, Suite 660 Dallas, TX 75254 Phone: (972) 503-3215 Fax: (972) 503-3219 Email: gharbert@nw14.esrd.net
Lori Hegel, RN, CNN	ESRD Network Quality Improvement Directors	Quality Improvement Director ESRD Network of Florida, Inc. 600 South Magnolia, Suite 300 Tampa, FL 33606 Phone: (813) 251-8686 Fax: (813) 251-3744 Email: lhegel@nw7.esrd.net
Barry A. Hong, PhD, ABPP	Psychologist	Professor of Medical Psychology Washington University School of Medicine Department of Psychiatry Campus Box 8134 660 S Euclid St Louis, MO 63110-1093 Phone: (314) 256-8796 (Wohl Clinic) Fax: (314) 362-4857 Email: HONGB@psychiatry.wustl.edu
Elizabeth (Liz) Howard, RN, CNN.....	DaVita, Inc.	Director of Policies and Procedures and Adverse Patient Occurrences DaVita, Inc. 4749 Grand Blvd. New Port Richey, FL 34652 Phone: (727) 844-0891 Fax: (727) 844-3093 Email: lhoward@davita.com

Mark Meier, MSW, LICSW.....	ESRD Network Patient Services Coordinators	Consumer Services Coordinator Renal Network of the Upper Midwest, Inc. 970 Raymond Avenue # 205 St. Paul, MN 55114 Phone: (651) 644-9877 Fax: (651) 644-9853 Email: mmeier@nw11.esrd.net
Jack Moore, MD.....	ESRD Network Medical Review Board Chairs	Section of Nephrology Washington Hospital Center 110 Irving Street, NW, Room 2A70 Washington, DC 20010 Phone: (202) 877-6034 Fax: (202) 877-8329 Email: jxm8@mhg.edu
Ida Sarsitis.....	Centers for Medicare & Medicaid Services (CMS)	Technical Advisor Centers for Medicare & Medicaid Services 7500 Security Boulevard, MS S3-02-01 Baltimore, MD 21244-1850 Phone: (410) 786-0066 Fax: (410) 786-8532 Email: isarsitis@cms.hhs.gov
Wendy Funk Schrag, LMSW, ACSW.....	Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation and Renal Care Group (RCG)	Patient Services Manager Renal Care Group 625 Medical Center Drive Newton, KS 67114 Phone: (316) 519-8018 Fax: (316) 284-9812 Email: wschrag@renalcaregroup.com
John Stivelman, MD.....	Renal Physicians Association (RPA)	Northwest Kidney Center 700 Broadway Seattle, WA 98122 Phone: (206) 292-2771 Fax: (206) 860-5821 Email: jstivel@u.washington.edu
Ann Stivers	National Renal Administrators Association (NRAA)	Dialysis Center of Lincoln, Inc. 7910 "O" Street Lincoln, NE 68510 Phone: (402) 489-5339 Fax: (402) 489-7366 Email: astivers@dialysisnebraska.org

Catherine M. Stokes	Association of Health Facility Survey Agencies (AHFSA)	Chief of the Bureau of Hospital and Ambulatory Services Office of Health Care Regulation Illinois Department of Public Health 525 West Jefferson Street, 4th Floor Springfield, IL 62761 Phone: (217) 782-7412 Fax: (217) 524-0382 Email: cstokes@idph.state.il.us
Lisa Taylor, BSN, RN	The Forum of ESRD Networks	Executive Director ESRD Network #12 7505 NW Tiffany Springs Parkway Suite 230 Kansas City, MO 64153 Phone: (816) 880-9990 Fax: (816) 880-9088 Email: ltaylor@nw12.esrd.net
William J. Winslade, PhD, JD.....	Ethicist	1416 Frontier Lane Friendswood, TX 77546 Phone: (409) 772-9393 (Work) Phone: (832) 545-6663 (Cell) Email: dray@utmb.edu

Dialysis Patient-Provider Conflict:
Designing a Collaborative Action Plan with the ESRD Stakeholders
National Consensus Conference
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Hilton St. Louis Airport

REVISED LIST OF OBSERVERS

Network	Representative	Title
Network 1	Roberta Bachelder, MA	Patient Services & Resources Coordinator
Network 2	Rick Russo, MSW, CSW	Coordinator of Consumer Relations/Community Development
Network 4	Dean Morris, MSSA	Patient Services Coordinator
Network 5	Nancy Armistead, MPA Liz Anderson, MSW	Executive Director Social Services Director
Network 6	Jenna Krisher Emily Hodgin, BSN, RN, CNN, CPHQ	Executive Director Director of Quality Improvement
Network 9/10	Susan A. Stark Kathi Niccum, ED.D.	Executive Director Patient Services Coordinator
Network 11	Diane Carlson Jan Deane, RN, CNN	Executive Director Quality Improvement Director
Network 12	Maggie Gellens, MD	Network Executive Council Chair-Elect
Network 13	Patricia Philliber Patrick Murphy, LCSW	Executive Director Patient Services Director
Network 14	Alex Rosenblum, BSRN, CNN, CPHQ Ramiro Valdez, MSW, PhD	Quality Management Coordinator Patient Services Coordinator
Network 15	Darlene Rodgers, BSN, RN, CNN, CPHQ Barb Campbell, MSW, ACSW, LSW	Executive Director Director, Patient Services
Network 16	MaryLou Pederson, RN, MA	Patient Services Coordinator/QI Support
Network 17	Joan Brenta, RN	Patient Services Coordinator
Network 18	Cecilia Torres-Correa, RN, BSN	Patient Services Coordinator

APPENDIX B

Discussion Paper

DIALYSIS PATIENT-PROVIDER CONFLICT (DPPC)

Discussion Paper for Designing a Collaborative Action Plan with ESRD Stakeholders August 2003

Prepared by:

Shari Rudavsky, PhD (CWA, Ltd.)
Peter Schwartz MD, PhD (CWA, Ltd.)

CWA, Ltd.

Interactive Management Consultants

Prepared for:

The Forum of ESRD Networks

A National Consensus Conference

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St. Louis, Missouri

Introduction

In the late 1970s a California woman earned the somewhat dubious distinction of becoming the first publicly recognized dialysis "problem patient." Despite repeated admonitions from her nephrologist, Brenda Payton used drugs, ignored dietary restrictions, and perpetually missed or came late to treatment appointments. Finally, her physician said she was no longer welcome in his outpatient dialysis unit.

His decision sparked a court case that proceeded through the courts to the California Court of Appeals. In 1982, two years after Dr. Weaver refused to treat Payton, the court ruled that he had the right to do so. In the decision handed down, however, the justices recognized the delicate nature of the matter before them. "Occasionally a case will challenge the ability of the law, and society, to cope effectively and sensitively with fundamental problems of human existence. This is such a case," the unanimous opinion read.[1]

Two decades later, the entire dialysis field struggles with patients who, like Payton, display non-compliant or otherwise problematic behaviors. During the past 20 years, the number of people with End Stage Renal Disease (ESRD) on dialysis has increased to about 350,000.[2] Many in the field sense that along with the increase in numbers there's been a rise in tension between dialysis patients and providers. They fear that patient dismissal or discharge has grown increasingly common and that not all cases of discharge are justifiable. While difficult patients may be a small percentage of all patients with ESRD, they command a disproportionate amount of many unit staff's time, many in the field say. Patients exhibiting challenging behaviors place their own health at risk, as well as the health of other patients and even practitioners. With the

[1] Payton v. Weaver. 131 Cal. App. 3d 38; 182 Cal. Rptr. 225; 1982 Cal. App.
[2] 2002 Annual Report, National Kidney Foundation.

number of patients on dialysis projected to double by 2010,[3] some in the dialysis community want to address this situation now, to find ways to reduce the potential for conflict and improve the work environment for professionals and the prognosis for patients.

Scope of Attention for Dialysis Patient-Provider Conflict Workshop: To address these concerns, The Forum of ESRD Networks is convening a workshop on October 2-3, 2003, in St. Louis, with physicians, nurses, patients, facility administrators, ESRD Network personnel, and others involved with dialysis to discuss ways to respond to difficult patients. The triggering question for the stakeholder workshop is as follows: **What are the challenges (or problems) that the stakeholders of the ESRD community must address to make progress in resolving the issue of conflict in dialysis facilities?**

Members of CWA, Ltd. (CWA) – an interactive management consulting company – will facilitate the workshop utilizing the ***CogniScope***™ system methodology (www.CWALtd.com). This "Discussion Paper" has been prepared by CWA, Ltd., to orient participants to relevant information and trends. It is based on interviews with 17 experts and leaders in relevant areas, along with a limited review of the popular and medical literature. This paper is intended as a review of some salient issues and literature for the workshop participants. There is no intent to publish.

Overview

The observations and opinions of the interviewees varied widely, and this report attempts to characterize this breadth of perspective. The report contains three sections that examine the following areas in depth:

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[3] Beth Baker. "Earlier Kidney Testing Urged," The Washington Post, Feb. 5, 2002, F1.

- **Causes for increased patient-provider conflict in dialysis units**

Interviewees and studies suggest numerous possible causes for the increased perception of conflict in dialysis units, and the report begins by describing some of these putative causes. These include: changes in the patient population; changes in the organization of dialysis units and increased reliance on ancillary health care workers; and limited resources for investigating and reacting to social and/ or psychiatric problems.

- **Practice and ethics of discharging problem patients**

The potential to discharge problematic patients courses through all discussion of conflict in dialysis units. Patients have been discharged for a variety of reasons, ranging from verbal or physical abuse, to missed dialysis appointments, to non-compliance with medication or dietary restrictions. Estimates vary on how frequently this sanction is employed, what actions precipitate it, and when it is acceptable.

- **Innovative ways to defuse tensions and heading-off conflict**

Interviewees offered multiple ideas for addressing conflict in dialysis units. These proposals range from achieving better definitions for "non-compliance" to utilizing a variety of interventions to reduce tension and address situations before they get out of control. These proposals, like the rest of the report, are included to stimulate thought prior to the October workshop: Are these proposals that you could endorse? Do they suggest any other proposals or ways to conceptualize the problem?

Causes of Increased Conflict

Change in Patient Composition

In 1972 Congress established the End Stage Renal Disease program, approving the use of Medicare funds to support dialysis or transplantation for most patients requiring these treatments

to stay alive. Prior to that time, dialysis was available only to a select few, and these patients would rarely cause problems, said many participants who have been in the field since its inception. Patients had to petition so-called "God committees" for access to the new technology. Not surprisingly, those panels turned down undesirable patients, and, said one respondent, favored middle-aged, white men with jobs. Once approved, patients were loath to do anything to jeopardize their dialysis. "They were extremely eager to get there. They followed everything you said to the letter," one respondent recalled. Even in the early years of Medicare reimbursement, most patients were compliant. "You had a culture of patients that just seemed to be more in tune with following rules. They were just thankful to be able to receive treatment to save them from dying," said one respondent who has worked in dialysis for more than 15 years.

But as the patient population expanded, so did the potential for conflict. Dialysis progressively became a privilege available to all, respondents noted, and that led to a dramatic change in the demographics of the patients who received it. "When you take anybody who has this diagnosis of kidney failure, clearly you will get a lot of people you wouldn't invite into your living room," said one respondent. Dialysis providers now had not just model patients in their care but also those who persisted to eat poorly, drink alcohol, or take illicit drugs despite recommendations against this behavior. As another respondent rhetorically asked, "Are you by random sampling going to have an increase in the number of people who are threatening because the base pool is no longer cherry picked?"

Certainly all participants agree that problems in dialysis units have increased dramatically since the program's early years. Few details are known, though. The ESRD Networks do not

systematically track these patients.[4] Little effort has been made to track problem patients over the long term, with professionals relying more on perceptions and anecdotal evidence than hard data. "Do we have the numbers to support this? It could have been an ugly secret that's been under the table for 10 years," suggested one participant, proposing that what's new here is not necessarily the way the patients act but the way facilities respond.

Societal changes may also have played a role, others note. While there have always been problems with abusive or threatening patients, said one respondent who has worked in dialysis for more than 25 years, "today it seems to be a little more acute because we're in a more litigious environment." If a patient threatens to sue the unit, a staff member may respond defensively and negatively, furthering tensions, this respondent said. "When patients threaten to get attorneys involved, that puts a little more tension in it," this interviewee added.

In addition, patients have grown increasingly savvy about their care and more willing to question professional authority. It's not a trend restricted to dialysis but it takes on new dimensions in this setting where patients and providers interact frequently. Obtaining the proper vascular access is one area that gives rise to much conflict, noted one respondent. A prior negative experience with one staff member can leave a patient reluctant to have that person cannulate (or insert needles for dialysis) them again. Many more patients today may be aware of their perceived right equest an alternative staff member. The staff, for their part, may try to ignore the patient's request.[5] "That is not the answer," said one respondent. "You can't say you have no choice. The patient sitting in the chair is the one feeling the pain."

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[4]Ramiro Valdez. "The Intolerance of Zero Tolerance," Dialysis and Transplantation, September 2001.
[5]In some cases, the facility's "Patients Rights and Responsibilities" document explicitly excludes patients from selecting staff, one provider noted.

Other changes also have affected the overall atmosphere in dialysis clinics. As the patient population has grown larger, so have many dialysis units. Many who have been in the field for a while fondly recall days when the units didn't feel as corporate. "It was more of a family type atmosphere," said one respondent who currently works in a small town unit that has 55 patients. Recalled another interviewee, who has also been in the field for decades, patients used to enjoy blankets and cups of ice while connected to the machines. "Now there's precious little for these patients to be comforted by," this participant said.

External factors may also trickle down into the dialysis unit, changing the nature of the relationship between patient and provider. For instance, one respondent who works in the legal office of one of the country's largest providers of dialysis noticed a dramatic increase in calls after September 11, 2001. The international events had an impact on the way the company responded. "We saw a jump in calls into this office about issues that had previously gone unreported," the interviewee said. "Because of our heightened sense of what was going on in the world, our advice was we couldn't allow a patient to continue to be threatening or abusive as long as we had previously allowed it to go." The general heightened awareness of danger in America may well still play a role.

Staffing Changes

Along with the changes in patient population have come equally dramatic changes in the demographics of those who care for these patients. In the early years of dialysis, recall many who were involved with the field, dialysis was a desirable specialty for nurses. Many who had trained in the high-powered worlds of the emergency or operating room eagerly made the switch to dialysis units. But in recent years there's been a shift in the type of person staffing the unit. The nationwide nursing shortage and increase in staffing costs have led more facilities to rely on less

trained technicians to do the jobs once covered by nurses.

Unlike nurses, these caregivers often are not steeped in a professional culture, many respondents agree. They don't receive as extensive or as thorough training as nurses. And their lack of professional and clinical preparation can affect not just their interactions with patients but also with coworkers, other respondents note. "This new generation is different," says one respondent, who has worked in the field nearly two decades. "The things that they dare to say even to their employers is different."

Some new hires may not have much previous healthcare experience and fail to inspire confidence in the wary eyes of patients, said one respondent. "These are big needles that get put in people's arms and one little error means you're over at the surgical center having your graft redone. You have people coming in who were literally security guards, burger flippers before they came to dialysis. As a patient you're not going to be able to trust some of them." In addition, the staff often has a strict schedule to follow and can't pause for assessment, intervention, or casual human interactions, others say. "Basically they're trying to get people on dialysis, off dialysis, and dealing with psychological problems falls far down the list," said another respondent. With patients spending three or four hours on the machine as compared to the six or seven once required, there's less time for these discussions, added another interviewee, saying "there's no time for amenities."

It's not just technical skill and time constraints that these lower-paid employees have working against them, others note. Nurses have extensive training in how to deal with people. These employees, who may have little more than a high school education and 30 hours of training, do not arrive in the clinic with the same people skills. As one interviewee said, "Technicians are not usually trained in the tender-loving-care aspect." While the more callous

might shrug and say that what these workers lack in training they compensate for in efficiency, this lack of training does come with a price, interviewees say. “They don’t have the expertise to handle the problems the patients bring to the table and they sometimes act in a defensive way when the patients bring them problems,” said one participant.

The change in who cares for the patient has frequently unrecognized consequences, note those with long-time experience in dialysis. One respondent recalls working in dialysis units 20 years ago when the ratio of patients to nurses was two or three to one. With such low patient-to-staff ratios, nurses could sit and talk with their patients, now a luxury. Those informal sessions offered ample opportunities for patients to air their grievances before their annoyance spiraled out of control. With the nursing shortage and even a limited number of technicians on the floor, the entire patient-provider interaction has changed, many say. “It’s become almost too business-like. There’s not as much courtesy in the units,” said another respondent with long experience in the field.

Even nurses can be fallible, some respondents note. “If you go into a unit you just have to know that not all staff is perfect. They’re not all the Lone Ranger wearing a white hat,” one interviewee said. “If you’ve ever worked in a small office with 10 people, can you imagine the possibility for conflicts? They’re great.” This respondent, a doctor, recalled an instance where one of his nurses mocked the new hairdo of one of the patients. The patient flew off the handle and started yelling at her, at which point the physician had to intervene. He chastised the nurse for her original comments and scolded the patient, saying that even if the nurse had been in the wrong, he should not have responded with vulgarities. “So that was defused and forgotten, but if I had acted in a different way that would have been smoldering and seething,” the interviewee said.

Nurses, themselves, are often overworked, others note, relegated to grueling and non-

patient-oriented paperwork that's become part and parcel of dialysis. The Centers for Medicare & Medicaid Services (CMS) is trying to alleviate that burden for nurses, said one respondent familiar with the effort. Currently many nurses have to enter quality improvement data twice – once for the ESRD Network and once for the facility's management. Now, CMS is encouraging corporations and Networks to standardize the process. "We think this can reduce the burden on nurses so they would have more time to spend with patients," said this participant.

Under different circumstances, social workers might be able to step in and fill this void, to reach out to patients in need of extra support, but dialysis social workers tend to be even more overworked than their nurse colleagues. Some social workers carry caseloads of almost 200 patients spread over a number of clinics, said one respondent familiar with the situation. Although the Council of Nephrology Social Workers recommends caseloads of 75,[6] social workers interviewed for this project said that few in the field actually have such manageable caseloads. "I'm pretty lucky. I have 94 patients," said one respondent. "Still there may be times when you can't see a patient for two weeks and so much can happen. If you were able to see them and provide intervention, you would catch these things and prevent issues from getting bad."

One nephrologist claims that the bottom line rests with the physician, who must set the tone and expect the rest of his or her staff to follow. "What you have to have is from the top down, an espirits d'corps that states that there will be disruptive patients because they're human beings and they're sick," this respondent said. "I'm a professional. I'm supposed to handle the hard stuff. In 85 percent of the cases, the staff has not done something right or the Medical Director is not involved enough or the Administrator has let the ball go and the first thing they want to do is discharge the patient without giving it the old college try."

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[6] Council of Nephrology Social Workers. Position Statement on Social Work Staffing, 1998.

Lack of A Strong Business Case for Quality

Increasingly, dialysis facilities and providers are being called upon to improve the quality of care for ESRD patients. Although most agree that this is an essential activity, it comes with additional costs. Time spent achieving unfunded yet mandated quality improvement programs adds staff stress as well as labor costs. Currently, facility reimbursement has decreased substantially in present value dollars. Given inflation, today's reimbursement for dialysis is equivalent to about $40 in 1973 dollars.[7] Also, costs continue to increase for providers, particularly the cost for nurses. Thus at a time when revenue is decreasing, costs are increasing.

Facilities are held accountable for their patient outcomes. Facility specific outcomes are provided for the public on the Dialysis Facility Compare website (http://www.medicare.gov/Dialysis/Home.asp.). These comparatives theoretically allow patients to make informed decisions about where they want to receive treatment, possibly impacting a facility's market share. Any effort to tie financial incentives to patient outcomes may inadvertently increase patient-provider conflict by increasing the "financial risk" of dialyzing non-compliant patients.

Finally, patients who miss dialysis appointments may decrease income since no bill can be submitted for a treatment not delivered. In a follow up to the 12 Network study, one Network found that 77% of the involuntary discharges for "non-compliance" were patients that skipped treatments, referred to as "no-show." These missed treatments clearly impact the financial viability of a facility, and since they are variable and thus unpredictable, are problematic in the business model. [8]

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[7] Allen R. Nissenson and Richard A. Rettig. "Medicare's End-Stage Renal Disease Program: Current Status And Future Prospects," Health Affairs January, 1999 - February, 1999.

[8] "Involuntary Patient Discharge Survey 2002. A Collaborative Network Project," March 27, 2003.

Dismissing Problem Patients

Uniform Language

A handful of interviewees expressed frustration with the language often employed in this discussion. As Brenda Payton's behavior more than two decades ago suggested, a variety of actions can lead to trouble for either the patient, the unit, or both. Many respondents readily ticked off a spectrum of difficult behavior, from the more innocuous to the most disruptive. Patients can refuse to take their medications or fail to comply with their diets. They can show up late, shorten, or skip their treatments. They can be verbally abusive to the staff or other patients, cursing at them or calling them names. They can threaten the staff or others verbally. They can threaten staff or others with a weapon. Finally, they can physically attack.

Currently, many in the community use the term "non-compliant" for all these patients, lumping together a wide variety of behaviors. But many respondents argue that this language obscures the issue. Some suggest that "non-compliant" should refer only to those in the first two categories (i.e., not taking medications or complying with diet); other respondents would include the third category as well (avoiding treatment). Clarifying the definition of what constitutes compliance, and articulating more clearly how to respond to various behaviors, might help staff at all units, this interviewee continued. Right now, a patient who shows up with a weapon might be allowed to continue at one unit, while a facility down the street discharges patients who fail to take their medication, said one respondent. "I would be very pleased if we agreed at least on the definitions," this respondent said. Creating a grade to rate conflict as low-level, mid-level, or high-level could help facilities decide how to respond when a patient engages in such behavior, another interviewee proposed.

One of the interviewees objected to the term "non-compliant," arguing for the term "non-adherent" in its stead. "Compliance suggests a hierarchical relationship, adherence is more shared decision making between the patient and provider," this respondent said. "It sounds like a lot of hand-waving, but it's a different way of looking at the relationship." And, of course, it also has different connotations for how or if at all the facility should respond when a patient fails to meet their expectations. Others have proposed that non-compliance be considered a failure of medical care, placing the onus for the breach on the provider, not the patient.[9]

No one disputes that abusive patients pose problems that must be dealt with. No respondent questioned the assumption that physical abuse constitutes grounds for dismissal. Indeed, under federal law, the unit has a responsibility to protect the well-being of its workers. But research suggests that physical abuse constitutes a small percentage of problems with patients. One study found that of 525 grievance or complaint calls, only 87 (16 percent) were related to disruptive or abusive patients, while an even smaller percentage, about 6 percent, regarded patient discharge.[10]

A different study of facilities in 12 Networks found that of about 200,000 patients seen, there were only 458 discharges, representing 0.2 percent of the patient population. Discharged patients were disproportionately male, African-American, and between the ages of 18 and 44, according to this survey. In 63.5 percent of the cases no sudden event had triggered the discharge, suggesting that a physical threat did not explain the decision. In fact, physical harm cropped up in only 36, or 7.9 percent, of the discharges cases, and physical threat played a role in

[9] N. Barber. "Should We Consider Non-Compliance a Medical Error?" Quality and Safety in Health Care 11(2002): 81-84.
[10] TransPacific. Renal Network Special Project on "The Patients (and Staff) Who Try Our Patience."

102, or 22.3 percent, of the cases.[11] Non-compliance was cited in nearly half of all dismissals, said one of the study's authors, and was the only reason given for discharge in one-quarter. Non-compliance included a range of actions, from being late to treatments to refusing a fistula. Verbal threat represented the second most common reason for discharge followed by verbal abuse. These results, said the study author, suggest that many in the field misinterpret how discharge should be used. "There's an overall lack of professional understanding of what non-compliance encompasses and how to deal with it," the interviewee said. "From an ethical standpoint this is creating a definition of non-compliance that doesn't fit the picture."

While the number of actual patients may be relatively small, from the perspective of many unit staff it looms large. As one interviewee said, noting the low percentage of patients discharged, "That doesn't sound like much but it consumes a whole lot of time on the part of the dialysis facility and it can consume a lot of time for the Networks if they get involved." Others argue that concentrating on the discharged patients obscures the broader tensions that rile units. Said another respondent, "There's been an enormous focus on the involuntarily dismissed patient and that number is so small, that I think we would do better as a community to discuss all the problems that lead up to it. We have more chance to deal with the unhappy staff and patients at that level instead of worrying about the very small number of people who get discharged."

Violent and Abusive Patients

Many of the respondents remembered the cases that had gone to discharge during their careers, cases where it appeared clear that dismissal was necessary: The drug-user whose violent outbreaks grew more and more violent until one day he appeared in the unit with a machete. The

[11]"Involuntary Patient Discharge Survey 2002. A Collaborative Network Project." See footnote 8.

mental patient who insisted that he had a right to bring his BB gun with him to the unit. The angry patient who threatened to see the doctor in the parking lot after work, prompting him to contact police. The elderly woman with dementia who had a habit of disconnecting herself from the machine "and using the blood tubing as the pope, anointing people," as related by one of the staff members who treated her. While in some cases other units picked up these patients[12] and had better success, few would argue that dismissal in these cases was unwarranted. As just about every respondent noted, dialysis facilities have a responsibility to ensure a safe workplace for their staff.

To that end, some companies take drastic steps to quell violence before it begins. One posts security guards in clinics where patients cause trouble, before making an effort to dismiss the patient. Over the years, the company has hired armed guards for about 50 units, said one respondent familiar with the policy. "I don't know if anybody has ever actually been injured, but it's more a sense of fear," the interviewee said. "The security guard is about general unease. A security guard can do a lot and it's on our dime, so it can do a lot to make everyone feel more at ease." But other respondents blanch at the idea of hiring security guards to keep peace. "If you have a security guard that means you're expected to use him," said one nephrologist, who oversees a unit in an inner city. "I have not had anybody do anything physical in 15 years. Any time it gets to that point, the staff is wrong. It should never have gotten to that point."

For at least a few patients, however, the reality is that it will get to that point. Then, a new set of questions arise, respondents note. Does the discharging unit have a responsibility to tell their colleagues elsewhere about the events that precipitated the dismissal, as some argue? Or

[12] In the case of the elderly woman, the unit required a family member to sit with her to try to keep her calm. When that solution, too, failed, alternative placement was found for her in an patient facility where she was able to be dialyzed in her own bed.

does the discharging unit have a specific responsibility not to prejudice others against the individual? Relations that boil over in one setting may stay perfectly cool in another, one interviewee argued, "A lot of times there's just a personality conflict between the patient and staff," this participant said. "If it's just somebody who's always at odds with Mrs. Jones and needs to be moved on, then I think they should be moved on."

Only about half of discharged patients do move on rapidly, noted another participant. One study found that about 50 percent of discharged patients find placement in another unit within a week. Another 22 percent rely on the emergency room and another 21 percent had an unknown outcome. Finally, 8 percent registered as "other," a category that one of the authors speculated might include death. Many interviewees who spoke about the difficulty of violent patients say they don't keep track of them after they walk out their doors, since the providers know that a hospital safety-net exists to treat those unwelcome in outpatient facilities. While this transfer of care strains an already overloaded resource, at least the dialysis units believe they are rarely a patient's last resort. Dialysis units of last resort -- such as the in-patient dialysis section at a large inner-city hospital run by one interviewee -- do not enjoy the luxury of dismissing patients. "The hospital has to take care of them. That's putting the hospital staff at risk with no recourse," this respondent complained. "We feel very powerless in this." In his city, about 25 such patients bounce from hospital to hospital for their care. Staff members have been attacked and the problem seems to be increasing. Ten years ago about two patients in this region fit this profile, five years ago it was about 10. Now, a staff member receives a threat about once a week. "You just hope they're not going to have a gun or a knife, that all it's going to be is verbal abuse," this respondent said. When this situation was mentioned to someone working in outpatient dialysis, that interviewee responded with a verbal version of a shrug, noting that

hospitals do have security guards to help keep patients in check. But there's little the guards can do, the hospital-based nephrologist counters: "Our security people are there to make sure that you don't park in the yellow lane. They're not police."

Still, as in just about every story, two sides exist. One of the people interviewed for this project confessed outright to having been a difficult patient. While on dialysis years ago, he had several run-ins with his providers. He begged the doctors to put him on a transplant list, but they refused repeatedly because of his drug use. Finally he told the unit doctor he wished to stop dialysis. In response she threatened to hold him for a psychiatric evaluation and called security guards. At that point, he pulled a gun and was arrested. Even to this day, the patient expresses no remorse for his actions. "All my experience with these people had been negative," he said. "I never felt that they were at all concerned with me." Once he found his way to another nephrologist, his outlook changed. He wound up on the transplant list, and years later he still recalls those original doctors with contempt. "They made it an us-against-them situation as opposed to how-can-we-get-you-through-this-tough-time. You want them to be on your side."

Defusing Tension and Addressing Conflict

Patient Autonomy/Compliance

Failure to understand particular aspects of a patient's point of view contributes in no small part to much of the tension that exists in units. For starters, there's the very nature of the disease. Patients may act out, unable to handle their rage against a disease that will shackle them to machines for the rest of their lives, irrationally angry with the individuals whom they perceive to be the agents of their illness. Other patients may find the unit a frightening experience, not just in terms of the other patients but also the staff on whose good will their lives in part rely. Inner-city patients may enter with a distrust and lack of understanding of medicine, one of the

respondents who works in just such an environment notes. They may not grasp medical concepts. One informal survey conducted in a major urban center 10 years ago of the least disruptive patients – "the little Caucasian ladies with knitting bags" – found that at least half lived in mortal fear of the staff, said one of the doctors involved. "They thought the staff wanted to kill them," the respondent said.

Even patients who do not fear the staff may dread the dialysis experience. Many patients experience physiological responses to dialysis that range from discomfort caused by restlessness, severe cramping, nausea and vomiting to serious episodes of loss of consciousness. While at times, even frequently, these symptoms are related to non-adherence to diet and fluids, they may also be dependent upon the skill and vigilance of staff. Patients frequently complain to the corporate office that owns the dialysis facility about being too cold in the unit or not having enough working television sets, said one respondent who fields such calls. Another respondent, a nephrologist who spends much time listening to disruptive patients' complaints, has heard complaints about myriad factors, ranging from poor lighting to a patient who blasts his radio. "A lot of these patients have very, very good reasons for being disruptive," this respondent said. "Not all of us have had the proper upbringing where we know how to complain." But even having the wherewithal to complain can be class, race, and education dependent, this doctor elaborated. Not every patient realizes that he or she can appeal to a higher authority if the unit staff member does not address the complaint.

One respondent who had a relative on dialysis noticed that on dialysis days he grew depressed and did not want to go. "It was very clinical and noisy with tile floors and beeping everywhere," the interviewee recalled. "It's just a room full of people staring at each other." On a few occasions, this participant said, another patient went into coronary arrest while on the

machine, which made her loved one even more loathe to go back. “When you sit in a chair three days a week next to the same man and you learn about his hobbies and you see him go into arrest, it’s a scary thing,” she said. “There’s always this sense of doom with patients on dialysis because they never know what’s going to be next.” Eventually, her relative went on peritoneal dialysis.

Patients may want to wrest some control over a situation that they feel has taken over their lives. If they choose not to follow a certain diet or skip on medications, they may do so not to annoy staff but to assert some control over their experience, many interviewees noted. Some units attempt to address this impulse by involving patients in their own care. They invite them to participate in patient-care conferences, even by phone, to assess ways to persuade the patients to make better lifestyle choices. “Sometimes their anger is about their inability to choose; they have very little control,” said one respondent. “We try to find out what kind of control they have given up and what they want.” Another interviewee, a psychologist, recommends that staff bargain with patients to bring them into compliance with their treatment regimens. One woman who always drank too much fluid between treatments had an affinity for watching the soaps. The staff told her if she arrived at the center with too much fluid, she could not watch her shows. “It was much more powerful than yelling at her,” this respondent said. “With every patient there are different things you can try. It’s not ‘one size fits all’.”

Of course, this can also raise the potential for conflict. What if a patient with poor lab values says that he will keep drinking alcohol despite the dangers? In this instance, the unit’s first instinct might be to wash their hands of the patient, one respondent acknowledges. But that would be as shortsighted as a physician dismissing a patient for failing to take medicine regularly. “If we discharge them for this, it’s not about conflict but about power, about who’s going to have the final word,” the interviewee said. For some patients, these attempts to exert

control will only backfire, others note. “It’s momma-daughter sometimes, ‘Don’t do that or I’ll shake my finger at you’,” said one facility administrator. “In the dialysis community we’re prone to be the overbearing parent figure and with some patients you just can’t do that.”

Many respondents compared the dialysis situation to oncology, noting that chemotherapy treatments, too, involve extended interactions with healthcare professionals over a long span of time. But the analogy is not a perfect one and the places where it fails illuminate potential for conflict. Chemotherapy aims to treat an acute situation and has a limited time span. Once on dialysis a patient will stay on dialysis indefinitely, in many cases.

Non-compliance

One respondent questioned whether non-compliance should ever be grounds for dismissal. “The difficulty I have is that the right of patient self-autonomy is a fundamental tenet of healthcare,” this nephrologist said. “If it’s non-adherence alone I don’t see why that should be grounds to dismiss someone from a dialysis unit.”

While many respondents agreed with the sentiment that non-compliance alone does not constitute grounds for discharge, just as many expressed fears - supported by the study quoted earlier -- that units nonetheless have started to do just that. This problem is not restricted to dialysis. Studies have found that nearly half of patients prescribed medication fail to take their drugs as directed.[13] “Non-compliance with medical treatments is not a new issue, but what the clinics are doing with it is a new issue,” this interviewee said. “Now it seems liable to discharge.” A little more than a decade ago, the practice of dismissal was virtually unheard of,

[13] Francesa Lunzer Kritz. “Pill Reminders at Our Age?: Alarming! High-Tech Time-for-Your-Dose Nags are Light Years Beyond Your Parents’ Plastic Pill Box,” Washington Post, Jan. 15, 2002. F01.

say many in the field.[14]

Non-compliant patients require counseling, not punitive measures, many respondents agreed. “If they skip the treatment, they’re only harming themselves, they’re not harming anyone else in the unit,” one interviewee replied. “They can’t discharge a patient because the patient is messing up their numbers, which I’ve heard of.” Patients may have very good reasons for failing to comply with aspects of treatment, other respondents noted. One recalled a grandmother whose grandchild was being abused by an alcoholic mother. The grandmother would not leave the house even for dialysis whenever she felt her granddaughter was at risk. Another respondent told of a woman in her unit whose poor compliance stemmed from her constant risk of eviction.

Some respondents argue that it’s critical to take the time to learn why the patient repeatedly fail to comply. One respondent told of a patient in her clinic who kept registering high potassium levels. This Vietnamese woman had no idea what in her diet could contribute such an abundance of potassium. Her favorite dish, she said, was noodle soup. Only when a staff dietitian sat down with her and delved deeper did she learn that the noodle soup also contained a type of bok choy that happened to be high in potassium.

Few respondents knew of cases in which units had discharged patients for such behavior, though some said they had heard rumors this occurred. Far more common, believed many interviewees, is the practice of discharging patients who repeatedly fail to show up for treatments. Not only is it legal to discharge such patients, units cannot be held responsible for any ill effects that ensue.[15] While some interviewed for this paper said that they could think of no situation in which such action is warranted, others argue that skipping or coming late to

[14] See, for instance, Ramiro Valdez, “The Intolerance of Zero Tolerance,” Dialysis and Transplantation, September 2001.
[15] James B. Riley and Robert Pristave. “Patient’s Right in Receiving or Rejecting Dialysis Care,” Nephrology News and Issues, 2001.

treatments impacts other patients scheduled for the same shift. Even a patient who is a few minutes late can throw off the rest of the shift, they note. And those who repeatedly skip can threaten the clinic's financial well-being. "You don't want to have a bunch of empty chairs out there when there's a waiting list for people to get into those chairs," said one respondent. "Dialysis is really a privilege. You have the privilege of being treated and taken care of."

More units, accordingly, start this discharge process for patients who become repeat no-shows. Many respondents, however, lambasted the practice, saying that few units put in writing how many absences are acceptable, making it rather arbitrary who falls victim to this punishment. Even those units that do have an official policy frequently give in to a visceral emotional response to a patient's frequent no-shows – a "three strikes and you're out" policy – without sitting down and talking to the patients about what obstacles may contribute to their repeat absenteeism, others say.

One respondent suggested that the motives that underlie facilities' willingness to discharge are far from pure. Arguing that little data exists to support the contention that these patients wind up consuming more healthcare resources, one nephrologist posited that units' self-interest guides such discharge decisions. As more facilities fall under scrutiny for patient outcomes, dismissing these recalcitrant patients will help improve their performance. "Five years ago the units were responsible only for getting you in," this respondent said. "Now patients who are non-adherent can worsen the performance of your dialysis unit. That's been argued to be a subtle prompt to get these patients out of your unit."

Alternative to Discharge

Few in the dialysis field see discharge as the solution to the problem. Instead, many proposed ways to avoid reaching the point where discharge appears to be the only answer.

Different facilities have taken different approaches, interviewees said. Some units have started requiring their staff to attend conflict-resolution seminars. At one company, for instance, within the first six months of employment every employee must attend a half-day seminar run by an outside company. At another unit, a minister visits five days a week. “It costs me $6,000 a year. Doesn’t every unit have $6,000 they can spare?” asked the Administrator. “To me that doesn’t seem like a huge price to pay to bring some peace and understanding.” In another area, the Network has trained six staff members as certified instructors in crisis prevention, and they intervene when a problem arises, said one respondent who went through the program. These trained specialists offer seminars for facility staff and others.

Simple measures could make a huge difference, many respondents argue. For many interviewees, the key is uncovering minor issues before they spiral out of control. Posting grievance boxes and ensuring that patients know how to register complaints could definitely help, one respondent notes. For instance, in one unit where he worked, the nurse would come out to the waiting room and brusquely scream out the names of patients to come inside. “A couple of people didn’t like that,” he recalled. “A guy who has a sixth grade education, when this nurse comes in or calls his name wrong or in a funny way and tells him to hurry up, he may just say kiss my ass.” More reticent patients may not feel comfortable voicing concerns, so another interviewee endorses patient-satisfaction surveys as a way to identify potential problems.

Attention to scheduling may also help, another respondent said. Never put two complainers on the same shift as they can “whip each other up.” In that participant’s unit, “We gave them all great shifts on different days. We used a little constructive psychology to make things better.” In other contexts, increasing patient contact may also help make a difference, other respondents say. Patient meetings and support groups offer an outlet to reach patients

where staff fail, one respondent suggested. Patients may have greater faith in another patient's recommendation than in the word of the staff. "I can sit and tell a patient all day long that they have to take a phosphate binder, but it doesn't have the same impact coming from me as it does from the patient whom they're dialyzing next to," this interviewee said.

In general, many agree that the process of orienting both patients and staff to the world of dialysis could be improved.[16] Most clinics hand a ream of information to patients when they first arrive, frequently confused, disoriented, and scared. "All this information is thrown at them. Corporations need to figure out how to do more patient orientation and do it in a more time-appropriate period," this respondent suggested. One of the hardest aspects of dialysis for patients to grasp at the beginning is that it is not a cure-all. They will continue to feel sick on many days and they will have to make major adjustments in their lifestyles to accommodate the rigorous dialysis schedule. "Patients come with high expectations," said another interviewee. "I don't think we do a good enough job about naming all of the disruptive things." Staff members may also not appreciate the patient's experience, said one social worker. "It's important for the staff to know how the patient feels. If you can get the staff in the patient's shoes, maybe have them sit in the chair for four hours taped down…"

All of these measures assume, however, that no underlying mental condition would preclude patients from responding well. Studies suggest, however, that 44 percent of all patients have depression at the start of dialysis. Only 16 percent of them receive treatment and only a quarter of those whose depression is severe are being treated.[17] Since other studies have shown

[16] For a very complete discussion of what such orientation could consist of, see Ramiro Valdez, "Is an 'Ounce of Prevention' the Key to Working With the Aggressive Dialysis Patient," Nephrology Incite, Issue 10, iKidney's online professional journal (www.iKidney.com).
[17] S. Watnick. American Journal of Kidney Disease 41(June 2003).

that the odds are three times greater that depressed patients will be non-compliant,[18] addressing this depression early on could lead to lower rates of non-compliance.

Perhaps all patients should routinely undergo a psychiatric evaluation before starting dialysis, proposed one respondent. This evaluation could help identify those most likely to turn into an abusive patient and help direct him towards anger management programs or counseling. In some clinics early identification of mental problems is already routine. One nephrologist interviewed who runs urban, inner-city dialysis centers carefully screens each patients to ensure that they can see, hear, and do not have an underlying mental illness, all conditions that can play into a patient's disruptive behavior. "What I want to find out early is why someone would go tell the head nurse to go [expletive] herself."

Those patients who do require more help would do well to see a counselor regularly, several respondents argue. "We're an outpatient dialysis unit, not an outpatient psychiatric unit," one interviewee said. Another, a psychologist who has worked in the dialysis field for 25 years, said he believes he could help in many cases, but that the staff he works with appear to view him only as a measure of last resort. "Most dialysis units send these people to me when they're at wit's end," this respondent said. "I think there are more referrals that I could get, but the dialysis units only send me the train wreck cases." Even in the extreme cases, his expertise has proved beneficial. In one instance he recalled, he examined a woman who was on the verge of dismissal and detected that she had a limited sort of brain damage, a fact that had eluded the dialysis staff. Once the staff learned that a physical disability helped explain her actions, they became more sympathetic to her.

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[18] M.R. DiMatteo. Archives of Internal Medicine 160 (2000): 2102-2107.

Other interviewees offered more drastic, time-consuming solutions. An in-hospital dialysis provider, clearly frustrated with having to treat every patient regardless of the situation, proposed that the dialysis community just stop providing care to those who are unwilling or unable to comply with the rules. None of these individuals, many of whom are mentally ill or drug users, thrive on dialysis, he argued. Rather, he said, the treatment just prolongs the inevitable. "There's a miserable long-term prognosis for these people. It's a form of society-sanctioned suicide," said this participant. "Because we will not deal with these issues we're going to allow this group of people to self-destruct and until they self-destruct, we put other people at risk of being hurt by them. When you bend over a patient to listen to his heart, you have no idea what he's going to do."

Another nephrologist, who once had a police escort after a patient threatened to kill him, agrees that discontinuing a patient's right to dialysis should be an option. Guidelines do exist to help guide healthcare professionals as to when it is or is not appropriate to begin and end dialysis.[19] These guidelines includes a section devoted to disruptive patients, but acknowledged the challenges they can pose. The section begins: "The Working Group did not make specific recommendations regarding these issues because they were considered beyond the scope of the guideline charge and there was no real consensus about what to do with disruptive patients."[20]

It is this type of patient – the person who has decision-making abilities, desires to remain alive, but continues to engage in behavior that interferes with care – that the above nephrologist was addressing. He proposed that rather than shifting these patients from facility to facility, a process be developed to allow the system to cease treatment. "Someone has to say this

[19]"Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis," Renal Physicians Association and American Society of Nephrology, January 2000.
[20] Section 5 of the Clinical Practice Guidelines (see footnote 18).

is like advanced cancer or advanced heart failure. We reach a point where we can't treat you," he said, adding that he knew of at least three nurses killed by patients. "At some point you just have to say I quit, I'm not going to take care of you." Given the import of such decisions, this interviewee proposed that the government be responsible for deciding when a person should no longer be treated. Committees comprised of social workers, ethicists, doctors, priests, and others could convene to decide a patient's fate, similar to the so-called "God committees" that predated the advent of widespread dialysis, this respondent suggested. One less dramatic step, others have suggested, would be to create separate facilities for the most difficult patients.

Summary

Many in the dialysis field appear resigned to the fact that at least some conflict will arise in the patient-provider relationship. "There's no question that there's a segment of the dialysis population that's not a pleasure to deal with, but this is medicine," said one nephrologist. Still, many also fear that the drastic step of discharge is rapidly becoming an easy fix for too many units. In an effort to improve both patient care and the staff's work environment, then, ever increasing number of dialysis professionals have vowed to explore the issue to ameliorate the problem as much as possible. Interviewees welcomed the idea of a project that focuses on this topic, saying that much could be done to improve the situation.

As this paper has enumerated, multiple challenges must be addressed along the way. However, respondents described interventions that may help decrease conflict in certain situations. Some of the innovative ideas were:

- Improving orientation procedures for patients and staff
- Instituting mechanisms for patients to make suggestions or air grievances

- Utilizing support groups or other ways for patients to help each other
- Using religious resources, including clergy, in the unit
- Increasing psychological screening, counseling, and treatment

Many other proposals are suggested above, and other ideas will occur to readers of this report. All stakeholders, after all, have experience with the issues being aired here. This report's description of conflict in dialysis units and possible steps forward are just a start. In October participants will have the opportunity to develop their understanding and proposals much further.

APPENDIX

INTERVIEW LIST

Nephrologists:
Jack Moore, MD
Section of Nephrology
Washington Hospital Center
Washington, DC 20010

William F. Owen, Jr., MD
Renal Physicians Association
Chief Scientist, Baxter International Healthcare, Renal
Adjunct Professor of Medicine, Duke University School of Medicine
McGaw Park, Illinois 60085-6730

Godfrey Burns, MD
St. Vincents Hospital
New York, NY 10011

Family Member:
National Kidney Foundation Family Council
Susan M. Belkin
Port Saint Lucie, FL 34986

Patient:
Roger Strahl
Albuquerque, NM 87109

Renal Community

Clinical Nurse:
Rusty Smith, RN, CNN
DaVita Bedford
Bedford, Texas 76022

AAKP - Patient:
Brenda Dyson, President
American Association of Kidney Patients
Tampa, FL 33607

Social Worker:
Norma J. Knowles, MSW, LCSW
Dialysis Clinics, Inc.
Columbia, MO 65201

NRAA

Ann Stivers
CEO/Administrator
Dialysis Center of Lincoln, Incorporated
Lincoln, NE 68510

Dialysis Chains

Legal representative – FMC:
Deborah Gifford Casey, Esq.
Associate General Counsel
Fresenius Medical Care North America

CMO – FMC:
J. Michael Lazarus, MD, Senior Vice President and Medical Director
Fresenius Medical Care, N.A.
Lexington, MA

Nurse – RCG:
Carolyn E. Latham, RN, MSN, MBA, CNN
Corporate Vice President, Clinical Operations
Renal Care Group
Nashville, TN 37203

Legal:
Mr. Richard Feferman, Esq.
Feferman & Warren
Albuquerque, NM

Psychologist:
Barry A. Hong, PhD
Ballwin, MO 63011

ESRD Networks
Executive Director:
Arlene Sukolsky
TransPacific Renal Network
San Rafael, CA

Patient Services Coordinator:
Mark Meier, MSW
Renal Network of the Upper Midwest, Inc.
St. Paul, MN 55114

Centers for Medicare & Medicaid Services:
Ida Sarsitis
Technical Advisor
Centers for Medicare & Medicaid Services
Baltimore, MD

APPENDIX C

Clarification of Challenges

Table 1: Preliminary Clarification of Challenges for Addressing the DPPC Situation

Triggering Question:

"In light of the ideas presented in the Discussion Paper on the DPPC project, what are challenges (or problems) that the stakeholders of the ESRD community must address to make progress in resolving the issue of conflict in dialysis facilities?"

(1 - Challenge) VALUING PATIENT AUTONOMY

By that we mean that each patient and their choices are honored and respected by every member of the healthcare treatment team.

(2 - Challenge) COMPOSITION OF THE STAFF

A: This is the changing composition of people who care

From primarily professional to non trained health care provider

Q: what do you mean by non trained

They don't have professional education.

Q: Are you saying it is negative change?

R: No is changed.

Does these have to do with LPNs or RNs?

Our thought was composition.

Q: Can you be more specific re: training?

R: We mean numbers.

Q: Do you mean increase in ratio?

R: Yes, there is change in composition of care providers. I don't want ration because it doesn't apply to all

Q: Do you mean it's an obstacle, how does it contribute?

R: Our thought is it is partly workload and partly skill sets in numbers of health care team.

Q: Is it possible to describe what you mean? Identify what you mean by staff. Define staff like a sentence.

R: Presents a challenge from workload standpoint and skill sets of people providing care.

(3 - Challenge) LACK OF ADEQUATE STAFF TRAINING (CRISIS INTERVENTION AND CONFLICT MANAGEMENT)

We were talking about crisis intervention and conflict resolution, primarily to increase training for floor staff but provide that training to all people who work in the dialysis center.

(4 - Challenge) CREATE MECHANISMS FOR RESOLVING CONFLICTS

A: Needs policies or guidelines on how conflicts can be voice and resolved, informally, professional intervention, diagram of how conflict can be handled

Q: Should clinics create the mechanism?

R: We need mechanism for staff no matter where you are on flow chart structure set up ahead of time to resolve issue.

Q: Does this differ from grievance?

R: May need different levels, formal, informal psychosocial evaluation involving the medical director, or some array so people know where to go to resolve the issue.

Q: So we add more?

R: No, we need to look for other approaches that grievance procedures, i.e. if there is problem with a staff person, where do you go? If we had a flow chart for patients/staff, they would know where to go.

Q: Do you mean we need to standardize the process across facilities or within facilities?

R: I think every facility needs to develop their diagram.

(5 - Challenge) BALANCING THE RIGHTS OF OTHER ESRD PATIENTS

This is just a consideration of how a dialysis clinic works – there's an open treatment floor so if one patient is abusive or loud or frightening, he's violating the rights of all other patients in room. Just trying to balance that patient's right to life-sustaining treatment with other patients' rights to be given dialysis in a safe environment.

(6 - Challenge) LACK OF SUFFICIENT PAYMENT TO HANDLE RESOURCE INTENSIVE PATIENTS

A: This is not agency position. Don't mean more payment but differential payment. No incentive to kick patients out but get pay appropriately for extra care patients need.

(7 - Challenge) LACK OF STAFF TIME TO DEAL WITH ROOT CAUSE OF PATIENT BEHAVIOR

We were talking about, primarily due to the workload, the lack of time staff members have now just to talk with their patients, to find out what other underlying causes might be present contributing to that behavior. This lack of time is often viewed as an excuse by the patient, although it is truly a reality and often times that will result in conflict all by itself.

(8 - Challenge) DEFINING THE EXPECTATIONS OF BOTH THE STAFF AND PATIENTS IN THE UNIT

A: Talking about expectations and responsibilities of staff and facilities and responsibilities of patient of unit. What are their expectations when they come into unit.

Q: Could this be split up into one for patients and one for staff? Should also be one that covers role of Social worker?

R: We feel staff have expectations of patient to be compliant and follow rules. Patient may have different expectation. Did not include social workers but more about staff, want to go home don't want to stay her but patient comply within timeframe. It is the interaction.

Q: Do you mean conflict in expectation of patient?

R: Conflict between what patient has and expectation of staff to do 4 hr /3 hr, eat right food. Conflict between expectations.

(9 - Challenge) ESRD STAFF (INCLUDING NEPHROLOGISTS) SHORTAGES

The person power shortages lead to less time and less ability to manage conflict.

Q: Why is that limited to nephrologists and nurses?

A: Point taken, we could change nursing and nephrologists to ESRD staff. I'm very comfortable with that. It might be clearer if we also put parenthetically nephrologists so we're all clear that doctors are included here.

(10 - Challenge) DEVELOPING MEASURES OF OUTCOMES AND ACCOUNTABILITY THAT ADJUST FOR PATIENT PREFERENCES

A: Acknowledging this is area of disclosure of data, and increasing pressure for accountability. Facilities are sensitive to allowing patients to exercise choice because of impact on measures. Measures must have a way to adjust to patient choice and how it impacts those measures

Q: What do you mean by patient choice?

R: Adherence or non and how it effects outcomes.

Q: Do you mean modality of or to have or not have?

R: Patients taking medications, not showing, etc. Could be modality

Q: Is a better word for choice lifestyle/ preferences?

R: I accept preferences.

Q: Struck with data on shortages is it outcome?

R: Relates to how to capture data collection on these issues.

(11 - Challenge) FOCUSING ATTENTION ON PREVENTION OF PROBLEMS INSTEAD OF WAITING TO REACT

I noticed that when the situation blows up and there's a crisis, that's when a lot of attention is paid to particular situations. It would be much better to have prevention at the individual level rather than wait until things are really explosive.

(12 - Challenge) AN UNDERUTILIZATION OF THE CLINIC SOCIAL WORKER WHO IS EMPLOYED AND TRAINED TO PREVENT CONFLICT

A: Each facility is mandated to provide for Social Worker coverage.

Social Workers have to take a more proactive role in assisting clinics in dealing with conflict.

Q: Do you mean only Social Workers or other clinical staff?

R: We were focusing on Social Workers being social workers and allowing nurses to be nurses, etc. focusing on those who are clinically trained to deal with this issue.

C: Role of Social Worker is not clearly defined. They have to evaluate social needs, transportation, at the bottom. Then make sure all coverages are taken care of but not taking care of psychosocial needs.

Q: Would you accept putting in social workers so we know who you are referring to?

R: Yes.

Q: Are you implying the social worker is there when patient is dialyzing?

A: How about who is employed?

(13 - Challenge) CONSISTENT AND ONGOING USE OF PSYCHIATRIC AND PSYCHOLOGICAL CONSULTANTS

This is generally wrongly asked, psychiatrists and psychologists are often asked to come in after a problem is there. They could actually utilize us before. We could be available and used at times other than under emergent situations.

Q: When you talk about the use of them, are you talking about helping staff as well as patients?
A: Staff and patients, just across the board, both.

Q: You mean consistent and ongoing?
A: That's a good way to say it.

Q: Do you really mean a lack of?
A: In some places, it's a lack of, in some places it's not consistent use.

Q: Do you mean onsite attention provided by the facility or do you mean a referral to an outside specialist?

A: It could be both. Sometimes it's necessary to go on site, other times this can be referred to somebody in an office.

Q: So this would be financed by the patient's health insurer?
A: I wasn't addressing that.

(14 - Challenge) DISRUPTIVE PATIENTS MOST LIKELY FEEL MISUNDERSTOOD AND DEPRIVED

A: We think this is a root cause of abusive and violent behavior.

Q: Is that primarily due to communication issues?

R: That would be one factor.

Q: Is that sometimes or all the time, does that include all patients or some?

R: I was not prepared to say all and always, most patient are likely to feel misunderstood.

Q: Does this come from what is acceptable from some areas of society and ethic backgrounds that is not acceptable for others?

R: No.

Q: Can we restate this more positively?

R: That is not what we meant.

Q: Proposing an amendment that is more generalizable?

R: We are making a comment about how patients feel. It is true they need to be understood but that's not what we meant.

C: The statement is good. I know patients that feel deprived due to situation. They make decisions between buying medications and food.

C: This is true if you include it.

C: The statement says that.

Q: You are not saying all, but they are always likely feeling misunderstood? There are exceptions?

R: No, they are likely.

Q: Do you mean clinic staff or globally by life situation?

R: I mean in the context of dialysis treatment.

(15 - Challenge) NEED FOR THE MEDICAL DIRECTOR TO TAKE A STRENGTHENED AND VISIBLE ROLE IN THE FACILITIES

The patient is the leader of the team, but the physician is the leader of the clinical team. We would like him to be involved in planning and leading clinical team as much as possible. The more they are around, the less we expect these problems will occur.

Q: Are you saying there is a need for the medical director to see this need?

A: That is correct.

Q: Would you mean that to say strengthened and visible role?

A: That is good. Maybe we can put "need for medical director to take a strengthened role in clinic".

Q: I would just like to comment, a basic observation to go along with this statement, in working with patients in facilities at the network level, there are many nephrologists who do not have an interest in working through conflict between patient and provider at the facility.

Q: Were you envisioning both or one of the other – having the medical director round more, so he's out on treatment floor more, or the medical director having more of a role in policies?

A: Both. We have listened and also proposed changing payment for nephrologists, so both of those.

Q: Do we want to include all nephrologists or just medical directors, because some facilities have a medical director but other nephrologists also attend there.

A: That's one of the most difficult pieces in program – attendings, how do we get them on board. If we're talking about cap payment, we're talking about all physicians. We're trying to get more interaction through various venues. Maybe we could say all physicians…

Response from floor: No!

A: Let's leave it that way because the medical director is the one who's responsible.

Q: I'm glad he left it the way it is. This is just a comment, even though medical director may not like to get involved in conflict, he doesn't have to get involved himself, but he has a responsibility to make sure that conflict is dealt with by somebody in the unit.

A: Even though the physician may not always be able to resolve it, he or she can direct it to the right people or resolve a lot of them before they become problems.

Q: The medical director is obligated to ensure that the facility is safe for both patients and staff, therefore it is emphatically the medical director's issue or problem to take a role.

Q: When you say strengthened role, do you mean the medical director then is very active with the medical staff in terms of the staff bylaws and all of that?

A: Yes.

(16 - Challenge) LACK OF ATTENTION BY ALL RENAL STAFF TO PATIENT NEEDS'

A: We talked about many staff being afraid to ask patients questions because they may not want to deal with the response the patient may give. Staff may talk to patients briefly and not get into the true issues. It is an issue of professionalism, whether they are trained through schooling, the facility or their ability to deal with people in general. There is a lack of physician involvement in facility.

C: It may not always be the staff's fault because patients don't always say what's bothering them but keep it in until it explodes.

C: Yes, we were referring to staff/patient interaction.

(17 - Challenge) UNIT POLICIES NOT ENFORCED WITH CONSISTENCY THAT COULD PREVENT SOME OF THE CONFLICTS THAT ARISE

I was talking about a situation that I'm familiar with: Usually the unit has policies about relationship between patients and caregivers. There was a situation where the unit ignored or failed to see the relationship between a patient and staff member. The patient got to the point where he only wanted that staff member to work on him. Any one else that worked on him was a problem and he was discharged. But if the policy had said from the beginning that this staff member should not have worked on him, it would not have gotten to the point where that patient had to be displaced from that unit.

(18 - Challenge) AN INCREASE OF THE NUMBER OF PATIENTS WITH INTENSE SOCIAL NEEDS

A: It is intuitive, patients are sicker and sicker with greater and greater needs. There are more of them. There is no hidden agenda.

The disease disproportionately affects managed persons. They bring it to the table when they come.

(19 - Challenge) ENSURING THAT PATIENTS WHO ARE INVOLUNTARILY DISCHARGED HAVE ACCESS TO REGULAR DIALYSIS

This speaks to the observation of what is occurring where patients are dismissed involuntarily from dialysis facilities, without placement for dialysis, it could be because non-compliance, non-adherence, whatever. The result is they do not receive regular dialysis which we all know they need to survive and we have a program in this country to ensure that almost all patients who need it do get regular dialysis and these people are being shut out from that.

Q: One question I have is do you want to include this, this is really a result, whereas we're trying to worry about the cause. This is kind of an after-effect. Do you see it this way?

A: I see it as a big challenge in resolving this issue.

Q: I'm not aware of any other situation in healthcare where a violent person can continue to demand healthcare at the expense of other patients. I wonder if we're going to have to talk about violent patients. When people are violent, maybe they abdicate their right to dialysis.

Q: Are you saying that facilities should be responsible for placing the person?
A: The obstacle is that when patients are voluntarily discharged without placement, they have no means to receive regular dialysis. That's a big challenge.

Q: Would an exception to this be that that patient who chooses not to receive regular dialysis, the would choose to shorten treatment?

A: That's a good point, that patients who want dialysis get it.

Q: Is this meant to speak to entitlement as to undocumented aliens?
A: No, I did not think of that when I made this statement. It is not included.

Q: Ensuring that all eligible patients get this?
A: I accept that.

Q: When I read that now, okay, that doesn't include undocumented people in United States, but now I'm wondering about that farmwife that never worked a day in her life, people that are not eligible for

Medicare benefits for a variety of other reasons, but have lived here all their lives.

A: Not thinking of those situations when I made this. I was thinking of people already in the system who get discharged.

Q: I've limited my scope to those who are patients with conflicts and possible conflicts, not to the whole community?

A: I was speaking about patients who get voluntarily discharged.

Q: Would you be willing to add patients who are currently on or receiving dialysis so we're not including all those other people. A: (on revised statement): This means patients who are already in the system receiving dialysis who are tossed out of the unit for whatever reason, that those who want to continue living have regular access to that care.

(20 - Challenge) FINDING A WAY TO GET CORPORATE BUY-IN AT THE EXECUTIVE LEVEL

A: This relates to when we were discussing the role of Social Worker and getting corporate buy in for their role, developing an appreciation of higher level of patient conflict and amount of resources need to address it.

C: The most effective way to get it is to have a close family member as a patient.

(21 - Challenge) A MISMATCH BETWEEN STAFF EXPECTATION OF PATIENT BEHAVIOR AND THE INFLUENCE OF A CHRONIC ILLNESS ON A PATIENT'S BEHAVIOR

Clinic staff frequently discount the challenges patients deal with in terms of chronic illness, in terms of increased incidences of depression, poverty issues, family issues, there's just a multitude of issues. Some of our patients have anemia or uremia problems that also affect their behavior. When patients are on dialysis their moods change during the course of their treatment. Staff are not changing the same as patients and therefore not are understanding where patients are when conflict arises.

(22 - Challenge) LIMITED REGULATORY GUIDANCE REGARDING PATIENT TERMINATION

A: This is about the ESRD regulations as written. It allows discharge for non-payment of fees but disregards the welfare of other patients. The networks give different interpretations of the regulations. Every patient situation is different. There should be more defined regulatory guidance.

It fails to address the rights of staff required to provide safe work environments.

Q: Do you mean there is inconsistent federal regulatory guidance?

R: Yes, there is a lack of consistent regulatory guidance but my issue includes more. There is one regulation for all and it is vague.

C: We will look forward to your comments when regulations come out.

R: I will keep the statement as is.

C: I think these are different issues. Patient termination is not due to violence.

R: I can divide them.

Q: Does your statement include orderly transfer?

R: Yes.

Author decided to divide the statement into two statements. See item #36.

(23 - Challenge) LACK OF CONSISTENT ENFORCEMENT OF FEDERAL REGULATIONS THAT COULD DEAL WITH THE ROOT CAUSES

As many reports have said and all of us are aware, we could do a better job of enforcing the regulations out there and providing consistent guidance on our expectations. There's too much variability between networks and service providers.

(24 - Challenge) LACK OF TRUST OF PROVIDERS BY PATIENTS

A: In the larger society, patients don't trust caregivers, and this is increasingly true in dialysis facilities. Due to the nature of care, patients may be in fear for their safety. It may have to do with their trust in whether staff is well trained.

(25 - Challenge) EDUCATING THE STAKEHOLDERS OF THE VALUE OF CUSTOMER SERVICE

When we were talking about educating masses, units in many situations have become almost like assembly lines, move them in, get dialysis done, and move them out. Everyone is so busy that they don't have time to sit down with patient. You can sit down with any patient for just a few minutes and find out way more than you ever thought you could. I think we have moved away from that, treating the customer as an individual. The second part of that is knowing who are the customers and that takes in more than just who are the patients.

Q: I was a little confused about what you mean by masses.

A: That's a good question, all of the stakeholders and primarily the staff who care for the patients, so I don't mind changing that if that's more clarifying. Stakeholders would be your owners and staff, it would not necessarily incorporate government and network because I think they already know. But by stakeholders I mean everybody.

(26 - Challenge) FACILITY AND PROFESSIONAL FEARS OF BEING PUNISHED FOR POOR OUTCOMES

A: This has to do with accountability.

(27 - Challenge) THE INFLUENCE OF FAILURE TO CONFORM BY ONE PATIENT ON THE BEHAVIOR OF OTHER PATIENTS

Those of us who have worked in a dialysis unit have observed this many times. It's a mini-society of its own. If one patient begins signing off early, let's say, the other patients want to do that too. You might have a facility where a patient transfer comes in, and he can come off early and other patients say, wait a minute how came he gets off early. It can also work in a positive way, with patient counseling in a positive way.

(28 - Challenge) THE PROVIDER'S FEAR OF LITIGATION (E.G. ABILITY TO TOLERATE A DEGREE OF RISK INSTEAD OF DISCHARGING A PATIENT)

A: In corporate work there is an increased use of attorneys to help corporations stay in safe position. There's a fear of litigation such as, What if we let a patient come in, and they bring a gun and shoot people. There is a fear of catastrophe.

(29 - Challenge) INEFFECTIVE GRIEVANCE MECHANISMS AT THE CLINIC, NETWORK, STATE AND FEDERAL LEVEL

We meant for that to read state but I said federal. The clinics, the networks, and the state health departments all have mechanisms to handle grievances, but we felt that there are aspects of all grievance policies that do not allow for patients who feel they will be retaliated against it. We just felt that there's some refining that could be done with all these grievance policies.

Q: I'm just glad you mentioned the elephant in the room, retribution. It's a major issue we have to deal with. We are interested in having a standardized grievance process, so we could track and trend, because that's worked… we need to have a better idea. We need to have our fingers on the pulse of what's going on so we can guide program appropriately.

Q: Why did you exclude federal?
A: Maybe it's my misunderstanding.

Q: But we're all public servants and there's nothing more effective at making a regional office effective than a grievance.

(30 - Challenge) LACK OF INITIAL COMPREHENSIVE PSYCHOSOCIAL ASSESSMENTS

A: This means everyone should have assessments that include assessment of cognitive ability, personality coping, psychological disorder, etc. I don't think everyone views it this way across facilities.

Q: Would this be a lack of comprehensive assessment?

R: Some do it, some don't.

Statement was amended

(31 - Challenge) FOCUSING ON TREATMENT AS A HEALING ART RATHER THAN TREATING PATIENTS AS REVENUE UNITS

This is intended to address the impersonality of the process and treating the whole process as providing a commodity service, almost as a commercial exchange rather than recognizing that this arises out of

medicine and caring for a sick person.

Q: That would make the care of ESRD uniquely different than the care of any other class of patients, would it not? I don't want you to think I'm naïve, but I think one of the barriers to resolution is a real-politik understanding of what the business is, for that's what this is, a business, whether we like it or not. I don't really understand, until we change the whole system from top down or top up how a different mindset is going to be able to take place.

A: It accommodates and recognizes that it is a business.

Q: If you just treated it, give it the Walmart standard, the same standard of politeness you give in Walmart, you don't have to choose between healing arts and revenue units.

(32 - Challenge) LACK OF UNDERSTANDING OF THE RESPONSIBILITY THE CLINICS / FACILITIES TO THE PATIENTS' FAMILY MEMBERS

A: It has to do with facilities having the rights and responsibilities for patients, and who to deal with families of patient. Understanding how to bring patients' families into the decision making process.

Q: Does this include HIPAA law of requirement to restrain notification of family member when the family member is part of the problem?

R: Yes, recognizing you can only involve family when patient agrees in accordance with HIPAA.

(33 - Challenge) LACK OF DOCTOR, NURSES, PATIENT CARE TECHS., SOCIAL WORKERS, ETC. LACK OF ABILITY TO RECOGNIZE THEIR PERSONAL BIASES

Primarily we talked about the experiences that people bring with them into the facility and how they will affect their ability to deal with patient behaviors. They all remember a patient who may have threatened them in past, or a family member who was irresponsible and that will cause them to judge other patients based on that particular experience.

(34 - Challenge) FINDING DOLLARS AND WAYS TO RETAIN QUALIFIED STAFF REDUCING TURNOVER

A: Addressing turn over of staff is a huge issue in this community. When dollars are short, units have difficulty finding dollars to retain staff or continually train, staff resulting from turnover. Finding dollars is catch 22. If you don't spend dollars you have poor care or if you spend the dollars you sacrifice other tings.

(35 - Challenge) RESPONSIBILITY SHIFTING WITH INNER CITY HOSPITALS BECOMING REPOSITORIES OF OTHER PEOPLES PROBLEMS

In the medical vernacular, we're referring to dumping, where it's easier to refer a "problem patient" rather than solve the problem, you just take it off your plate and put it on somebody else's.

(36 - Challenge) REGULATIONS FAIL TO ADDRESS FEDERAL LAWS REQUIRING A SAFE WORK ENVIRONMENT

Q: Does this mean General Counsel is not doing their job?

R: It says that the only grounds for termination, does not include OSHA, and it fails to address existing federal law.

(37 - Challenge) KNOWING WHO ARE THE CUSTOMERS

Knowing who are the customers because we have a number of them – our staff in providing safe work environments, patients and families who have expectations of the dialysis unit to treat the whole person, because the family is often thousands of miles away so they expect the unit to do the jobs of a family member. Physicians, who have needs, government. Just everybody.

(38 - Challenge) *INVOLVING THE ATTENDING PHYSICIAN TO TAKE AN INCREASED ROLE WITH THEIR PATIENTS*

Q: What does this mean?

A: It means each physician needs to be aware of what behaviors their patients exhibit and to be involved with resolution of the problems patients exhibit.

(39 - Challenge) INCREASE IN THE NUMBER OF SOCIAL PROBLEMS AFFECTING THE STAFF

Just the increase not only in the number, #18 talked about number of social problems facing patients, but I think we have seen an increase in the number of social problems affecting our staff as well.

(40 - Challenge) THE CULTURAL DISPARITIES IN WHAT IS DEEMED AS ACCEPTABLE BEHAVIOR

A: Some behavior is acceptable with one ethnic population and not acceptable in others (e.g. loud talking, cursing, etc.) Until a person is taught that their behavior is not acceptable we should not throw them out.

Q: Does that mean disparities between facilities?

R: Yes, it could very well.

Q: Does it include that staff and patients may have different ethnic mixes?

R: Yes.

(41 - Challenge) MANAGING CRIMINAL BEHAVIOR BY A PATIENT IN A DIALYSIS CLINIC

Patients that steal your computers, sexually expose themselves, make sexual assaults on staff, sell drugs, that kind of behavior.

(42 - Challenge) LACK OF RESEARCH OR UNDERSTANDING OF THE EFFECT ON STAFF MEMBERS WORKING IN DIALYSIS

A: This will go hand in hand with item 43. Lack of understanding of the emotion impact on care providers when a chronic patient they care for becomes critically ill.

Staffs are often affected deeply when someone illness worsens or they die. It effects how they deal with other patients.

(43 - Challenge) HOW DO WE PROVIDE THE RESOURCES AND SUPPORT TO COMBAT THE CONSTANT STRESS, GRIEF, LOSS AND COMPASSION FATIGUE THAT IMPACTS STAFF AND THEIR ABILITY TO PROVIDE COMPASSIONATE, PROFESSIONAL CARE

This does go along with #42, but the fact that we want the staff to get very close to the patient and the patients expect them to be an extension of their family, but they do get close, and patients do die, and we need to have staff deal with loss and grief and still allow them to be professional and compassionate.

(44 - Challenge) THE VARYING PERCEPTIONS AMONG PROVIDERS AND PATIENTS ABOUT THE IMPLICATIONS OF TREATMENT FOR ESRD BEING AN ENTITLEMENT

A: This is the elephant in the living room. Entitlement has legal implications. The sense of entitlement effects how patients behave and if affects staff. Staff can be angry about patients doing what they want. End stage renal disease being only disease that has an entitlement.

Q: Does this mean it is the root of patient problem?

R: It applies to people with this disease and they are entitled to emergency room setting as well as others services. In the handout we received, the word "privilege" is repeated. This is not clear in minds of people who wrote the text. In assessing roots of this context, we have to define "what is treatment". The patient is entitled this does not mean a privilege and that shades how we provide services.

Q: Does this include that the patient has rights and responsibilities? Patients don't understand both. The term entitlement carries negative baggage.

R: Operationally it is true. Patients are entitled, to hell with rest of you because I am entitled.

(45 - Challenge) LACK OF APPLICATION OF HOLISTIC AN ALTERNATIVE MEDICINE MODELS IN THE DIALYSIS CLINIC

I'm speaking of what can happen in dialysis unit when we become technicians, just providing renal replacement therapy and not addressing all the needs of the patient all the time.

Q: I don't understand. How does that apply to holistic care?

A: Holistic health means you're addressing the person in their totality, not just for their one medical need.

Q: But it's lack of application, are you advocating there should be holistic medicine or there shouldn't be?

A: There should be. But that's a value statement. I'm just making an observation at this point.

Q: Do you mean that the nephrologist is not performing the functions of the primary care physician to the dialysis patient? Is that the drift of this?

A: That's part of it, yes.

(46 - Challenge) PATIENT FEAR OF RETALIATION

A: Patients being afraid to discuss things they are concerned about because the fear retaliation by staff.

Q: Does this include patients who do complain and feel this way?

Q: Or patients who have experienced retaliation by staff?

R: Yes.

(47 - Challenge) LACK OF CKD EDUCATION IN PRE-ESRD PATIENTS AFFECTS PATIENT ADJUSTMENT ON DIALYSIS

This is just referring to the fact that we do have some patients that enter into dialysis and they don't even realize they have a chronic condition. They look at it as they're going to be treated and cured. This is just reacting to that, that they didn't realize this is a chronic condition.

(48 - Challenge) PROVOCATIVE BEHAVIOR BY PROFESSIONALS LEADING TO PATIENT DISRUPTION

A: Many forms of provocative behavior that are subtle and affect patient reactions. If staffs are resentful because of being overworked, underpaid, cynical, cranky causes patients and be disruptive.

(49 - Challenge) NEED TO UNDERSTAND STAFFS' FEELING OF FAILURE WHEN PATIENTS DO NOT FOLLOW THEIR ADVICE

I think a lot of nurses, techs, social workers and physicians, everyone, just kind of take it personally and feel let down when they give someone advice and they don't follow it. It's just more non-adherence.

Q: I think that sometimes that can lead to aggressive behavior, because staff goes back to patient and says you didn't do this and patient gets angry and we need to recognize that's why this is happening.

(50 - Challenge) STANDARD OF EDUCATION FOR STAFF

A: This is important. I have worked in different units for different companies and chains and found there is a different education requirement level in each. This happens from one unit to another unit in the same city. It is different. The standard of education for technicians needs to be there so they understand what they do, how to do it. This hold emphasis gives the patient more confidence that they know what they are doing. The paper provides a good example of a person flipping burgers one day and serving as a provider the next day. If you employ people you must bring them to certain standard. All dialysis units should have this, and until this issue is dealt with from technician we will continue to have issues. The staff who spends the most time with patients has no training requirement. Until this is dealt with we won't have services we want. This is an important part of resolving conflict. When we choose a doctor, we don't choose incompetent ones. When patients see someone that is not knowledgeable, the patient is not comfortable. Must have staff capable of performing the procedures. If you use them, they must get to a certain level of training.

Q: Do you mean the need for state or federal standards, or clinic standards/regulations?

R: Some clinics have good standards, and some have nothing. Until an organization with authority speaks up, there will be disparity.

Q: I'm not sure if you mean corporate or national educational programs?

R: Just like the person paying bill requires certain level of dialysis to get reimbursed, there should be a certain level of training for staff. It may be on paper that they have a certain level of training, but in reality it is not true.

(51 - Challenge) IS THE PRESENT STRUCTURE OF THE ESRD PROGRAM INTRINSICALLY DESIGNED TO GENERATE OPPOSING INTERESTS WHEN HEALTH CARE IS INCENTIVIZED

This is a long way around simply saying that in their essence there are conflicts between resource utilization, costs and noncompliance, and they are one of the biggest causes of noncompliance, depending on providers.

(52 - Challenge) FAILURE TO FULLY EDUCATE PATIENT AT START OF DIALYSIS ABOUT RIGHTS AND RESPONSIBILITIES

A: Most corporations intend to do this but sometimes it is given short attention. It is often abbreviated and the patient doesn't absorb what is said to them.

(53 - Challenge) LACK OF EVIDENCE OF THE EFFECTIVENESS OF BEHAVIOR CONTRACTS TO DEAL WITH PATIENT CONFLICTS

There's no clear-cut guidelines of research that substantiates the use of behavior contracts and many behavior contracts are being implemented to discharge patients. I don't think patients are given adequate opportunities to meet the constraints of many behavior contracts.

Q: Do you mean a lack of guidelines or lack of any evidence?

A: Would be happy to change to lack of any evidence.

Q: Are you saying there is no evidence basis for the efficacy of behavioral contracts?
A: Not that I'm aware of, no literature that I know of, but I have looked.

Q: Did I understand that you don't mean utilization, you mean effectiveness?
A: It becomes two different issues. I think it's a lack of guidelines for use of behaviors contracts and it's a lack of any evidence for the effectiveness of behavior contracts. I want to introduce another one (#66).

(54 - Challenge) NEED TO UNDERSTAND THE PATIENT'S LOSS OF CONTROL WHEN THEY HAVE TO FOLLOW EVERYBODY'S ADVICE ON EVERYTHING

A: I was speaking strictly as a patient. A patient loses control when everyone tells them what to do. When staff treats the patient like a child and not an adult, it leads to acting out on the patient's part.

(55 - Challenge) INSUFFICIENT OF NUMBERS AND TYPES OF PROFESSIONALS TO MANAGE CHALLENGING PATIENTS

This was to elaborate on how thinly stretched the staff feel, that each nurse wears a lot of different hats. At the one clinic where you may be having the problem or one event, security guard may not be there. Just the way they're staffed and how thinly staffed there are, just not having sufficient numbers or staffs to deal with it.

(56 - Challenge) CORPORATE EXECUTIVE OR REGULATORY CONTROL FAR FROM THE BEDSIDE

A: Sometimes organizations are complex. There are multiple layers and it is hard to get to people who make decisions about policies and guidelines.

C: That's why I am glad things have changed.

Q: Regarding corporate executive issues, do you mean business leadership or medical?

R: I was thinking business when made comment.

(57 - Challenge) FUNDING FOR PATIENTS WHO HAVE EXHAUSTED ALL RESOURCES THAT CAUSES THEM TO MAKE CHOICES BETWEEN HEALTHCARE AND EATING

That social workers will work with patients and they exhaust all resources for the 20 percent that the patient may still owe, they absolutely don't have money and because where poverty guidelines are, they don't have money for Medicare, they start getting bills, and a lot of times the patient says, I'm just going to quit dialysis, I'd be better off dead because I don't have the money. I have to choose between dialysis and even having a place to sleep.

(58 - Challenge) LACK OF DEFINED METHODOLOGY FOR COLLECTING DATA ABOUT DPPC

A: This refers to the ability to collect enough information about the conflict we are trying to describe in order to study it better.

(59 - Challenge) USE OF ZERO TOLERANCE POLICY

This is about zero tolerance policies that have been employed, they vary from corporation to corporation. The utilization and implementation of them vary from shift to shift. What zero tolerance means to one corporation and staff member is completely different from what it mean to another. We had a situation where a patient was discharged and when we got to the basis of it, he was discharged for giving dirty looks and that was part of their zero tolerance policy.

(60 - Challenge) FAILURE BY THE TREATMENT TEAM TO PERFORM INITIAL ASSESSMENTS IN A TIMELY MANNER

A: This may have to do with the short staff issue. Initial assessments made by the entire assessment team are not done as they should. Sometimes care planning happens before the entire team conducts assessment of patient.

(61 - Challenge) UNDERUTILIZATION BY FACILITIES OF CORPORATE SUPPORT SERVICES IN ADDRESSING CONFLICT SITUATIONS

What I was thinking when I said that, sometimes facilities try to handle situations on their own or for whatever reason may not make use of corporate resources available to them.

(62 - Challenge) PATIENTS WITH PROBABLE MENTAL HEALTH CONDITIONS WHO REFUSE PSYCHIATRIC CARE

A: Everyone in community has seen the statistics that from 1/4 to 1/3 of patients suffer from mental health conditions from mild depression to schizophrenia. Sometimes this is identified as the cause of their behavior. You can make referrals all day but patient will not get treatment. This affects other patients.

(63 - Challenge) LACK OF CONCURRENT QUALITY IMPROVEMENT PROGRAMS

It seems as though all of quality improvement is based on retrospective review rather than ongoing assessment and monitoring of staff. Everybody needs oversight. The state agency should not have to come into facility and tell a unit that the staff does not utilize effective infection control techniques.

(64 - Challenge) VARIABLE POLICIES FOR PSYCHIATRIC COMMITMENT BETWEEN STATES

A: A critical issue in providing psychotic or abusive patients with care is that in many states physicians are handcuffed from committing patients from mental health board. It is often done through intermediate boards. Patients do not have the physician's judgments in making that call. There is great geographic variability in providing adequate services in these instances.

Q: Does that include psychiatric commitment?

R: Yes.

(65 - Challenge) MAKE PROVIDERS ACCOUNTABLE ONLY FOR OUTCOMES OVER WHICH THEY HAVE CONTROL

It's a great challenge, as we move into accountability, the possibility of financially incentiving quality outcomes, but it's very challenging to tease out one component, one facility, one social worker, and be certain that person is accountable alone for the outcome rather than the entire milieu, the entire dialysis facility, or the entire socioeconomic status of patient. It has to do with actionability.

Q: Would also like to say, not just providers, but the whole ESRD community, including government and congress. The scary thing about this is having outcomes over which we have no control. There may be mandates that will be unfounded. Could this include everyone else in the ESRD community?

A: I agree with that, but I wonder whether that should be #66 or what the number is. The issue of unfounded mandates at a time when dialysis facility providers feel that their revenues are falling.

Q: I'm just concerned about which ones we can be accountable for. Some variables have to do with disease progression, adherence, idiopathic disease, disease management.

A: This gets into difference between patient outcomes and process outcomes. I'm talking about process outcomes, because there are process outcomes that professionals and facilities should be held accountable for.

(66 - Challenge) LACK OF GUIDELINES FOR THE UTILIZATION OF BEHAVIOR CONTRACTS TO DEAL WITH PATIENT CONFLICTS

A: See clarification for 53.

(67 - Challenge) THE FEAR OF MAKING PROVIDERS ACCOUNTABLE FOR MORE UNFUNDED MANDATES

For many facilities, especially smaller facilities, we've hit the wall. We cannot stretch our dollar farther than we've already stretched it. If this leads to more staff and other resources, we cannot do it. We don't have any money to do it, so we have to cut something out.

APPENDIX D

Challenge Clusters

Table 2: Classification of Challenges for Addressing the DPPC Situation

CLUSTER #1: THINKING / FEELING OF PATIENTS

(Challenge – 1) VALUING PATIENT AUTONOMY

(Challenge – 14) DISRUPTIVE PATIENTS MOST LIKELY FEEL MISUNDERSTOOD AND DEPRIVED

(Challenge – 16) LACK OF ATTENTION BY ALL RENAL STAFF TO PATIENT NEEDS'

(Challenge – 21) A MISMATCH BETWEEN STAFF EXPECTATION OF PATIENT BEHAVIOR AND THE INFLUENCE OF A CHRONIC ILLNESS ON A PATIENT'S BEHAVIOR

(Challenge – 24) LACK OF TRUST OF PROVIDERS BY PATIENTS

(Challenge – 32) LACK OF UNDERSTANDING OF THE RESPONSIBILITY THE CLINICS / FACILITIES TO THE PATIENTS' FAMILY MEMBERS

(Challenge – 40) THE CULTURAL DISPARITIES IN WHAT IS DEEMED AS ACCEPTABLE BEHAVIOR

(Challenge – 46) PATIENT FEAR OF RETALIATION

(Challenge – 54) NEED TO UNDERSTAND THE PATIENTS LOSS OF CONTROL WHEN THEY HAVE TO FOLLOW EVERYBODY'S ADVICE ON EVERYTHING

CLUSTER #2: INCENTIVES / DISINCENTIVES

(Challenge - 26) FACILITY AND PROFESSIONAL FEARS OF BEING PUNISHED FOR POOR OUTCOMES

(Challenge - 27) THE INFLUENCE OF FAILURE TO CONFORM BY ONE PATIENT ON THE BEHAVIOR OF OTHER PATIENTS

(Challenge - 28) THE PROVIDER'S FEAR OF LITIGATION (E.G. ABILITY TO TOLERATE A DEGREE OF RISK INSTEAD OF DISCHARGING A PATIENT)

(Challenge - 31) FOCUSING ON TREATMENT AS A HEALING ART RATHER THAN TREATING PATIENTS AS REVENUE UNITS

(Challenge - 35) RESPONSIBILITY SHIFTING WITH INNER CITY HOSPITALS BECOMING REPOSITORIES OF OTHER PEOPLES PROBLEMS

(Challenge - 51) IS THE PRESENT STRUCTURE OF THE ESRD PROGRAM INTRINSICALLY DESIGNED TO GENERATE OPPOSING INTERESTS WHEN HEALTH CARE IS INCENTICIVIZE

(Challenge - 65) MAKE PROVIDERS ACCOUNTABLE ONLY FOR OUTCOMES OVER WHICH THEY HAVE CONTROL

(Challenge - 67) THE FEAR OF MAKING PROVIDERS ACCOUNTABLE FOR MORE UNFUNDED MANDATES

CLUSTER #3: RESOURCE LIMITATION

(Challenge - 2) COMPOSITION OF THE STAFF

(Challenge - 6) LACK OF SUFFICIENT PAYMENT TO HANDLE RESOURCE INTENSIVE PATIENTS

(Challenge - 7) LACK OF STAFF TIME TO DEAL WITH ROOT CAUSE OF PATIENT BEHAVIOR

(Challenge - 8) DEFINING THE EXPECTATIONS OF BOTH THE STAFF AND PATIENTS IN THE UNIT

(Challenge - 9) ESRD STAFF (INCLUDING NEPHROLOGISTS) SHORTAGES

(Challenge - 18) AN INCREASE OF THE NUMBER OF PATIENTS WITH INTENSE SOCIAL NEEDS

(Challenge - 34) FINDING DOLLARS AND WAYS TO RETAIN QUALIFIED STAFF REDUCING TURNOVER

(Challenge - 55) INSUFFICIENT OF NUMBERS AND TYPES OF PROFESSIONALS TO MANAGE CHALLENGING PATIENTS

(Challenge - 57) FUNDING FOR PATIENTS WHO HAVE EXHAUSTED ALL RESOURCES THAT CAUSES THEM TO MAKE CHOICES BETWEEN HEALTHCARE AND EATING

Table 2: Classification of Challenges for Addressing the DPPC Situation

CLUSTER #4: INADEQUATE OR LACK OF POLICIES

(Challenge - 17) UNIT POLICIES NOT ENFORCED WITH CONSISTENCY THAT COULD PREVENT SOME OF THE CONFLICTS THAT ARISE

(Challenge - 23) LACK OF CONSISTENT ENFORCEMENT OF FEDERAL REGULATIONS THAT COULD DEAL WITH THE ROOT CAUSES

(Challenge – 29) INEFFECTIVE GRIEVANCE MECHANISMS AT THE CLINIC, NETWORK, STATE AND FEDERAL LEVEL

(Challenge – 36) REGULATIONS FAIL TO ADDRESS FEDERAL LAWS REQUIRING A SAFE WORK ENVIRONMENT

(Challenge – 44) THE VARYING PERCEPTIONS AMONG PROVIDERS AND PATIENTS ABOUT THE IMPLICATIONS OF TREATMENT FOR ESRD BEING AN ENTITLEMENT

(Challenge – 50) STANDARD OF EDUCATION FOR STAFF

(Challenge – 53) LACK OF EVIDENCE OF THE EFFECTIVENESS OF BEHAVIOR CONTRACTS TO DEAL WITH PATIENT CONFLICTS

(Challenge – 59) USE OF ZERO TOLERANCE POLICY

(Challenge – 62) PATIENTS WITH PROBABLE MENTAL HEALTH CONDITIONS WHO REFUSE PSYCHIATRIC CARE

(Challenge – 64) VARIABLE POLICIES FOR PSYCHIATRIC COMMITMENT BETWEEN STATES

(Challenge – 66) LACK OF GUIDELINES FOR THE UTILIZATION OF BEHAVIOR CONTRACTS TO DEAL WITH PATIENT CONFLICTS

CLUSTER #5: LEADERSHIP

(Challenge - 11) FOCUSING ATTENTION ON PREVENTION OF PROBLEMS INSTEAD OF WAITING TO REACT

(Challenge - 15) NEED FOR THE MEDICAL DIRECTOR TO TAKE A STRENGTHENED AND VISIBLE ROLE IN THE FACILITIES

(Challenge - 20) FINDING A WAY TO GET CORPORATE BUY-IN AT THE EXECUTIVE LEVEL

(Challenge - 38) INVOLVING THE ATTENDING PHYSICIAN TO TAKE AN INCREASED ROLE WITH THEIR PATIENTS

(Challenge - 56) CORPORATE EXECUTIVE OR REGULATORY CONTROL FAR FROM THE BEDSIDE

CLUSTER #6: ETHICS FOR ASSESSING PROBLEM, PROGRESS

(Challenge - 10) DEVELOPING MEASURES OF OUTCOMES AND ACCOUNTABILITY THAT ADJUST FOR PATIENT PREFERENCES

(Challenge - 58) LACK OF DEFINED METHODOLOGY FOR COLLECTING DATA ABOUT DPPC

(Challenge - 63) LACK OF CONCURRENT QUALITY IMPROVEMENT PROGRAMS

CLUSTER #7: INADEQUATE UTILIZATION OF AVAILABLE RESOURCE

(Challenge - 12) AN UNDERUTILIZATION OF THE CLINIC SOCIAL WORKER WHO IS EMPLOYED AND TRAINED TO PREVENT CONFLICT

(Challenge - 13) CONSISTENT AND ONGOING USE OF PSYCHIATRIC AND PSYCHOLOGICAL CONSULTANTS

(Challenge - 61) UNDERUTILIZATION BY FACILITIES OF CORPORATE SUPPORT SERVICES IN ADDRESSING CONFLICT SITUATIONS

CLUSTER #8: OVERSIGHT & POLICY ENFORCEMENT

(Challenge - 4) CREATE MECHANISMS FOR RESOLVING CONFLICTS

(Challenge - 22) LIMITED REGULATORY GUIDANCE REGARDING PATIENT TERMINATION

Table 2: Classification of Challenges for Addressing the DPPC Situation

CLUSTER #9: EDUCATION & TRAINING

(Challenge - 3) LACK OF ADEQUATE STAFF TRAINING (CRISIS INTERVENTION AND CONFLICT MANAGEMENT)

(Challenge - 25) EDUCATING THE STAKEHOLDERS OF THE VALUE OF CUSTOMER SERVICE

(Challenge - 33) LACK OF DOCTOR, NURSES, PATIENT CARE TECHS., SOCIAL WORKERS, ETC. LACK OF ABILITY TO RECOGNIZE THEIR PERSONAL BIASES

(Challenge - 37) KNOWING WHO ARE THE CUSTOMERS

CLUSTER #10: IMPAIRED CLINICAL UNDERSTANDING OF PATIENT STATUS

(Challenge - 30) LACK OF INITIAL COMPREHENSIVE PSYCHOSOCIAL ASSESSMENTS

(Challenge - 60) FAILURE BY THE TREATMENT TEAM TO PERFORM INITIAL ASSESSMENTS IN A TIMELY MANNER

CLUSTER #11: PATIENT EDUCATION

(Challenge - 47) LACK OF CKD EDUCATION IN PRE-ESRD PATIENTS AFFECTS PATIENT ADJUSTMENT ON DIALYSIS

(Challenge - 52) FAILURE TO FULLY EDUCATE PATIENT AT START OF DIALYSIS ABOUT RIGHTS AND RESPONSIBILITIES

CLUSTER #12: PROFESSIONAL PERFORMANCE

(Challenge – 39) INCREASE IN THE NUMBER OF SOCIAL PROBLEMS AFFECTING THE STAFF

(Challenge – 42) LACK OF RESEARCH OR UNDERSTANDING OF THE EFFECT ON STAFF MEMBERS WORKING IN DIALYSIS

(Challenge – 43) HOW DO WE PROVIDE THE RESOURCES AND SUPPORT TO COMBAT THE CONSTANT STRESS, GRIEF, LOSS AND COMPASSION FATIGUE THAT IMPACTS STAFF AND THEIR ABILITY TO PROVIDE COMPASSIONATE, PROFESSIONAL CARE

(Challenge – 45) LACK OF APPLICATION OF HOLISTIC AN ALTERNATIVE MEDICINE MODELS IN THE DIALYSIS CLINIC

(Challenge – 48) PROVOCATIVE BEHAVIOR BY PROFESSIONALS LEADING TO PATIENT DISRUPTION

(Challenge – 49) NEED TO UNDERSTAND STAFFS' FEELING OF FAILURE WHEN PATIENTS DO NOT FOLLOW THEIR ADVICE

CLUSTER # 13: PATIENT BEHAVIOR

(Challenge – 41) MANAGING CRIMINAL BEHAVIOR BY A PATIENT IN A DIALYSIS CLINIC

CLUSTER #14: ETHICAL ISSUES

(Challenge – 5) BALANCING THE RIGHTS OF OTHER ESRD PATIENTS

(Challenge – 19) ENSURING THAT PATIENTS WHO ARE INVOLUNTARILY DISCHARGED HAVE ACCESS TO REGULAR DIALYSIS

APPENDIX E

Clarification of Action Options

Table 3: List of Action Options and Preliminary Clarification for Addressing the System of Challenges

Triggering Question:
"What are options which, adopted and implemented by the community of stakeholders, will help in addressing the system of challenges?"

(Action Option 1) DEVELOP A FEEDBACK METHOD TO PROVIDE STAKEHOLDERS WITH THE DATA RESULTS

It really was just to provide a method, once we collected data, so data gets back to stakeholders.

Q: Do you mean a format for reporting, or just feeding back numbers?

R: This part was really just to be sure that there is feedback, so once we have data, to make sure we do something with the data.

(Action Option 2) HAVE THE NETWORKS AND/OR NIH AND/OR USRDS PROVIDE / INVENT A DATA GATHERING TOOL TO AID DATA COLLECTION AND METHODOLOGY

A: Are there any questions about this?

Q: Do you think the networks can do this?

R: Usually the work flows from NIH to the network.

Q: Do you need to put "and or" in the statement?

Statement was amended

Q: There is a current program called Client Performance Measures project that correlates databases. Is what you are proposing in addition to that?

R: Yes. This is a separate data-gathering project that would clarify and define the issue.

Q: Does the "and or" go between networks and NIH?

R: Yes.

C: In the core data set we will be working on this. CPS are population and these are specific. The data will be reported back to the networks. This will be brought into the data issue. Don't know if we want to bring both into this. We want to get this done quickly.

(Action Option 3) CLARIFY AND CODIFY THE RIGHTS AND OBLIGATIONS OF PROVIDERS AND PATIENTS WHO OPERATE WITHIN AN ENTITLEMENT SYSTEM

I think there was a fair amount of discussion yesterday about what exactly an entitlement program is. I think we are one and this is simply a suggestion for all of us who operate in system, including patients, to understand what this means, legal or otherwise.

Q: By codify, do you mean new legislation, conditions of coverage, federal standards…

R: To me, it means to lay out in clear language, not interpretable for the region or state. I'm just asking in layman's language what does this mean.

C: Now you know clearness and codify are two mutually exclusive things.

Q: Do you mean like a provider and patient's bill of rights?

R: Not only rights and responsibilities, but a very brief and concise statement of what the program is. This is ESRD, this is what it means to patients and providers. More than a bill of rights, it would have… I don't know exactly what I mean. It would not be subject to local interpretation. This is a federal program.

Q: So you're talking about federal interpretation of current entitlement laws?

R: I think since I and everyone else here pay taxes for it, yeah.

Q: A simple English interpretation?

R: Yeah.

(Action Option 4) UTILIZE THE NETWORK #17 WORKING GLOSSARY AS A STARTING TAXONOMY FOR DATA COLLECTION FOR DPPC

A: This work that network 17 and 18 did was funded by CMS and is good foundation for this (see info in notebook). Before defining methodology we need taxonomy to describe the situation. Since work has been done, this would jumpstart what we are doing.

Q: Could you use this as a start for a working document?

R: Yes.

C: These are nice descriptive glossaries but don't replace formal psychiatric diagnosis. You could use this descriptively but need formal documents. In the work done in 11 and 14 the survey indicated a lot of problems using psychiatric terms. Fear of labeling patients by someone who is not qualified to do this.

Not saying you can't proceed this way, there are real pitfalls to doing this you may won't someone qualified. Regarding adequate treatment if you don't do that you cut off from Mental Health services… We're not talking about diagnosis

Q: I agree. Psychiatric evaluations when a situation happen in the unit, people are looking for behaviors, psychiatric evaluations come later. If patient is abusive they are forget why the behavior is there

Q: Can we offer changes to statement?

Include suggestion about DSM 4 in, DSM 4 diagnosis,

The only thing network 35 did that I take exception to is the term nonconformity connotes molding of patients in preconceived way were non adherence

Statement amended

If we go beyond characterizing actions and labeling patients it becomes an ADA issue. Don't want networks getting into this. Cautioning against this.

I think the glossary is helpful this would be a nice way to get idea of what's going on. Need a clinical psychiatrist to make diagnosis.

(Action Option 5) AN INITIATIVE TO ADOPT STATISTICALLY VALID PROCESS MEASURE IN ADDITION TO PATIENT OUTCOMES FOR ACCOUNTABILITY

Sometimes in the heat of battle, I forget which side I'm on. Process measures are measures that characterize what we do to patients. Patient outcomes are measures of what happens to patients and they're distinctly different. Process measure can capture the intent of the professional to do the right thing, even if there's a disconnect with patient outcome that the professional and facility have no control over.

(Action Option 6) ADOPT THE SETTING OF A NATIONAL CURRICULUM / STANDARD OF EDUCATION FOR DIALYSIS TECHNICIANS

A: Author amended statement to include encourage or adopt. There are existing standards that won't cost units anything.

Q: Would you consider removing encourage?

Author accepted

Q: Do you mean uniform national standard?

That would be great but I don't see that happening. A national standard would be great.

Q: Would you add provide federal reimbursement?

Amended to include national standard

C: The term standard means the lowest allowable, not optimal or benchmark.

Number 17 Clarification was merged with #6

C: Standards and curriculum are different.

Item #6 amended to include curriculum

(Action Option 7) SUGGEST FUNDING AND RFA FOR EXTENSIVE GRANT TO FURTHER DEFINE THE QUERYING TOOLS

This is just to put out for a grant to further define querying tools to gather a mechanism for the data.

(Action Option 8) DEVELOP AN ALGORITHM FOR DETERMINING THE LEVEL OF DISRUPTIVE PATIENTS

A: Develop something that will help the staff determine what level of disruption it is, i.e. yelling, medium: yelling and profanities severe: striking out.

Table 3: List of Action Options and Preliminary Clarification for Addressing the System of Challenges

(Action Option 9) DEVELOP A MODEL STAFF TRAINING ON CRISIS INTERVENTION AND CONFLICT MANAGEMENT WITH THE SOCIAL WORKER AS INSTRUCTOR

This would be something that could be developed that would be a model staff training on crisis intervention and conflict management. Social workers would get trained to do a model program and they could go back to their units and train people there. This would help with the lack of staff training and underutilization of clinic social worker.

Q: Is it necessary to limit it with last phrase of social worker as instructor?

R: Yes. I'll just give you example from RCG. We felt like the social worker was the best person to train on customer service. And I see the same thing here. We've hopefully already received that training and we're the best team to do that.

Q: Could it be a professionally trained conflict resolution person, someone who has a degree outside the organization who could do it? We don't use our social worker because they have time constraints.

R: Social workers? (turns around to observers) They're saying no.

(Action Option 10) CLARIFY EXPECTATIONS OF STAKEHOLDERS ABOUT ENTITLEMENTS THROUGH EDUCATION ABOUT ETHICS AND LAW

A: I think of this as the opposite of federal guidelines coming from above. This is a grass roots process that includes patients, health care professionals, technicians, everyone. This should be discussed at the grass roots level. We have disagreements that need to be sorted out before issuing regulations. It could be initiated by networks but conducted at local level.

(Action Option 11) INCREASE REIMBURSEMENT IN KEEPING WITH INFLATION FOR DIALYSIS SO THAT FINANCIALLY STRETCHED CORPORATIONS CAN IMPLEMENT EDUCATIONAL AND OTHER INITIATIVES FOR DPPC

I know we've been talking a lot about an important issue, but it's also a narrow issue as far as corporate obligations. We're not just a dialysis provider, we're a healthcare provider. So all of the initiatives that come down from federal government have to be implemented by corporation. A good example of that is HIPAA. Most corporations spent half a million implementing HIPAA. All of the things we're talking about are going to cost money. Interviewed people before I came here, the message was very clear. We're stressed as far as we can. We would like money left over to try to do something about the disease. We're going to have to find a little more money somewhere for much more to be implemented.

Q: Would you consider adding after increase reimbursement, in keeping with inflation? Because I would suggest that that's been the error since 1973.

R: I think that would be fine.

C. That's not necessarily a bad thing, to attract capital into the market, shareholders will need to have decent return. We have been sympathetic to increases to get composite rate above water., We have supported and encouraged development of – we believe we should be paying a fair rate for dialysis services that let you be innovative and put in education so you can get best outcomes. If you can help us improve patient care and reduce hospitalization, we'd be more than happy to share that money with you. But just giving more money every year is an easy way out. We need to be smarter and work harder.

(Action Option 12) PLACE A CURRICULUM FOR ADDRESSING CONFLICT RESOLUTION IN THE CONDITIONS FOR COVERAGE

A: One way to enshrine this is to have in code and regulations a mechanism to assure conflict resolution is addressed by some prescribed format.

C: You need to put conflict resolution in the statement.

A: This is a recurring theme. Issues will be resolved in upcoming issues regarding coverage. We need to provide comments when opportunities come up.

Author agreed to amend statement.

(Action Option 13) DEVELOP STANDARDS (WITH ALLOWABLE EXCEPTIONS) FOR FACILITIES TO FOLLOW WHEN DEALING WITH BEHAVIORAL ISSUES

This could even complement what Ann had contributed earlier in terms of an algorithm. At the network level, I think we're seeing increase in facilities and corporations utilizing their zero tolerance policies for

immediate discharge. If a facility reports that a patient cussed out a nurse and their policy includes no cursing, that patient could be dismissed that day. I think if we can come up with some guidelines or standards for facilities to follow, even if it is a minimum, to give them suggestions how to handle these patients rather than resulting in immediate discharge. The document that's in our materials from the Network #17/18 study is a basis, where it talks about involuntary discharge and some interventions facilities can employ.

Q: Are you talking about regulations versus a national industry standard? What is your ideal?

R: To begin, a national industry standard would be sufficient, because there's extenuating circumstances that could arise in every situation, I don't know that we want a federal regulation for them to follow.

Q: We need to be careful what we wish for, we may just get it. Whenever we use the word standards, if author would allow with allowable exceptions. When we're talking about minimums, we're talking about removing Medicare eligibility, there should always be allowable exceptions.

R: I agree with that.

(Action Option 14) INCREASE AND COORDINATE FEDERAL QA & QI ACTIVITIES

A: The regulations are useless if they are not enforced. We have a resource in the ESRD networks to help facilities. We want them to help clinics, and independent providers involved. Many of them don't know how to do QI. They need additional resources to fix things before state surveyors come in. It is better to fix a problem before a problem. We don't want to shut them down. The ramifications are disturbing. We need to get the networks and state surveyors working together. This would be a better approach Federal improvements take time.

C: One hazard in a uniform approach is that what we collect analyze.

R: Yes.

Q: All facilities say they have QA or QI but don't address these problems specifically. Do we want to add language that focuses on this particular problem?

R: No, this is just our oversight of the program in general.

Q: Can we add language that speaks to getting this problem included?

Group decided to propose new item 40.

(Action Option 15) PROMOTE ONGOING DIALOGUE WITH STAKEHOLDERS AND IDENTIFY INTERDEPENDENT SELF-INTERESTS

It seems to me that there needs to be an understanding between the patients and the people who provide the care that they are interdependent. If these folks don't perform adequately, your dialysis isn't performed the way it should be. On the other hand, if you aren't civil to them, you're not going to get dialysis. It's a two-way street and I think the power relationship is ignored in dialysis facilities.

(Action Option 16) REQUIRE FACILITIES TO REPORT INVOLUNTARY DISCHARGES TO THE NETWORK

A: The data that networks collect does not currently include lost or follow up. There is no mechanism to gather involuntary discharges. There should be a mechanism to include this on an individual basis. When they occur have a phone call

C: We have a workgroup in the network working on this. We are developing a broad definition for but it does not include a call to the PSD.

Q: would you add to your statement, wording that gets to networks not just reporting but involvement and reporting to networks so they are involved in process?

A: For clarity, I will leave as is.

(Action Option 17) ESTABLISH A NATIONAL CURRICULUM FOR PCT TRAINING (*Delete*)

Dialysis, particularly corporation dialysis, is now interstate commerce in my humble, non-legal opinion and it is a national program. Let's have some national standards.

Q: How different is this from #6?

R: Just the difference between the word curriculum and standard. We can merge them.

Q: When you merge them are you going to distinguish between standards and curriculum? They are not one and the same.

C: Curriculum leads to standard.

R: Just use them both.

(Action Option 18) ENCOURAGE THE NETWORKS TO CONDUCT CONFLICT RESOLUTION TRAINING SESSIONS FOR FACILITIES

A: I have always been told that what networks do best is education, education and education. Social workers may not always have time to instruct facilities staff on conflict resolution. The networks can find a way to do this. They can find a way to do anything.

(Action Option 19) ADOPT COMPREHENSIVE REGULATIONS FOR THE PROCEDURES AND STANDARDS FOR LIMITING AND TERMINATING PATIENT SERVICES AT A FACILITY

This is the 600-pound gorilla, are there any questions? The program has been in existence since 1972, when Nixon was president, my hair came down to my shoulders, and we were involved in land war in Asia. Some things never change. I mean, there are detailed regulations that the IRS has and government publications dealing with how much money I can deduct for using my car for business purposes. There is nothing regarding what can essentially be a life and death decision for 360,000 people under this program. There's a disconnect.

Q: Fascinating and provocative. The question is whether or not for example in spinning this out, I'm not arguing pro or con. My question is does this overlap into becoming a civil rights issue.

R: Rules are two-edged swords. They establish a minimum standard that you have to meet, but they also establish a cover that if you meet them, you might be presumed to be acting reasonably. It's easier for an industry to take the bull by the horns and attempt to control what happens because if you don't, it's going to be determined by courts and not by the industry.

Q: Do you mean terminating benefits to a patient or terminating payment to a dialysis facility?
R: This is strictly about what happens to the patient, rather than consequences for a facility.

Q: So if a patient were to pull a gun in dialysis unit, that would be reason for Medicare program to stop paying benefits?

R: No.

C: There's a difference between terminating treatment and terminating benefits. We have no right to terminate benefits. So maybe you want to put terminating treatment at that facility.

(Action Option 20) INCLUDE TRAINING REGARDING ROLES OF ALL STAFF WITHIN THE FACILITY AND THE INTERDEPENDENCE OF EACH IN PROVIDING QUALITY PATIENT CENTERED CARE

A: We have been talking about education, that should include understanding all roles of everyone in the facilities and how we work together.

Q: Do you mean including patient cultural context, preferences, shared decision-making? Is this the definition of patient centered care?

R: Yes

(Action Option 21) DEVELOP A SIMPLE BROCHURE OUTLINING THE BASIC TENETS OF CRISIS INTERVENTION AND CONFLICT MANAGEMENT

With relatively little work, this group I think could develop a quick brochure. With relatively little work and some additional funding, this could be quickly distributed and put in the hands of clinical providers.

(Action Option 22) DEVELOP A TASK FORCE TO WORK ON THE DPPC RESEARCH PLAN AND ENUMERATE THE VARIABLES OF INTEREST AND THE ISSUES TO BE STUDIED

A: This is one of the next steps to help put together this plan.

(Action Option 23) ACTUALLY PERFORM A NATIONAL DATA COLLECTION AND ANALYZE THE DATA

Just wanted to make sure we actually collected the data and analyzed it first.

(Action Option 24) ADOPT AND USE THE WITHHOLDING AND WITHDRAWING GUIDELINES THAT HAVE BEEN DEVELOPED

A: In 1991 RPA-ASN developed clinical guidelines on decision making for withdrawal from dialysis. I want to see this happen.

(Action Option 25) DEVELOP MINIMUM STANDARDS, WITH ALLOWABLE DEMOGRAPHIC EXCEPTIONS, FOR STAFF TRAINING, RATIOS, AND COMPOSITION

Talk about a 300-pound gorilla. Think I'll let statement stand.

Q: Feasibility is not an issue if you put these up?

Cesar: We'll talk about that later.

Q: Are you talking about regulatory minimal standards?
R: Yes.

(Action Option 26) COLLECT NATIONAL DATA ON QUALITY OF LIFE AND PATIENT SATISFACTION MEASURES AND USE THEM IN THE SAME WAY YOU USE CPMS

A: This goes back to treating patient as whole person. Also ties to item 39.

Q: Would you consider including patient satisfaction, quality of life?

R: Yes.

(Action Option 27) REQUIRE PROVIDERS TO EDUCATE STAFF REGARDING PREVENTION OF CONFLICT RATHER THAN RELYING ON ZERO TOLERANCE AS A DISCHARGE POLICY

The intent was to promote prevention as a better way to address this rather than waiting until things erupt.

Q: That would not, in your mind's eye, that would not exclude zero tolerance policies?
R: I think zero tolerance policies have a place if used in incident of violence, but not because this person curses or we think they're annoying.

(Action Option 28) MAKE A BUSINESS CASE FOR IMPLEMENTING THE OPTIONS WE SEE HERE TODAY IN ORDER TO ENGAGE CORPORATIONS AND STAND ALONE DIALYSIS UNITS IN IMPLEMENTING THESE CHANGES

A: We need to go through these we should develop a cost benefit analysis to see if these proposals will lead to a cost savings, if it will be costly and will be a long-term benefit. We should determine if we solve this as a business proposal.

Q: Would this include analysis of results of data collection that we talked about?

R: Whatever projects or solutions we generate today we should include in that a business analysis.

(Action Option 29) DEVELOP UNIVERSAL RESPONSIBILITIES IN ADDITION TO RIGHTS FOR ALL PATIENTS RECEIVING DIALYSIS (*Delete*)

I would be willing to eliminate it because it is very close to #2, when I reread #3, it really was incorporated in it.

(Action Option 30) DEVELOP MEASURES OF OUTCOME AND ACCOUNTABILITY THAT ADJUST FOR PATIENT PREFERENCES AND RESOURCE UTILIZATION

A: This is part of the data collection system. Unless we can adjust data for patient preferences and resource utilization, we may find a hesitance from to cooperate. This may be related to an item generated by Dick.

Q: When you refer to account for patient preferences, do you mean that as we develop a measure we subtract patients that don't adhere to requirements?

R: Yes under a specified set of rules.

Q: Is it same as item #25?

R: No.

(Action Option 31) REQUIRE DATA OBSERVING STAFF COMPETENCIES, ESPECIALLY IN INFECTION CONTROL

In the time that I have been here, it has come home to me that the conflict between provider and patient and potential for violence is very clear. Well, the potential for infection is violence for the patient. You have to observe care. When I see the person taking care of the patient just kicking any type of infection control to hell and gone in front of the observer, that means it's standard of operation. You've got to observe care. That is not happening.

Q: Do you mean the patient safety movement, how we can minimize detrimental effects happening to patients?

R: Yes.

C: A lot of calls we get from patients is related to this and it's one of the things that makes patients angriest.

(Action Option 32) PARTNER WITH SOCIAL WORKERS TO UNDERSTAND AND UTILIZE THE CORE ELEMENTS ARE VALIDATED INSTRUMENTS AS PART OF THE PSYCHOSOCIAL EVALUATION

A: Author changed term to social workers and intent is to provide a valid educational tool.

Q: I think I probably understand your intent but you talk about evidence- based, what do you mean?

A: Referring to items such as quality of live, depression inventories, literacy tools, etc. I need another word.

Statement was amended.

Q: Is this about initial psychiatric evaluation?

R: Yes.

(Action Option 33) ENCOURAGE OPEN FORUMS AT FACILITIES SO THAT PATIENTS CAN SPEAK THEIR MINDS WITHOUT FEAR OF RETALIATION AND WITH THE ASSURANCE OF APPROPRIATE FOLLOW-UP

I think one of the problems with patients keeping things in is it does build up. I think if we encourage more open dialogue, patients can feel free of retribution.

Q: I agree with both parts of sentence, but I don't understand the logic. If there's an open forum, would that increase or decrease the fear of retaliation?

A: I wanted to encourage dialogue, but I didn't know how best to state it.

Q: I think that would have to include some sort of follow-up on what they learn from their comments. If I comment to you and nothing's done about it, I might get angry.

R: It might have to be at corporate level, but I don't have the particulars worked out and they say I don't have to.

Q: Would you be amenable to adding appropriate follow-up?
R: Yes.

(Action Option 34) LEVERAGE DIALYSIS UNITS TO "MAKE" SOCIAL WORKERS DO WHAT THEY'RE SUPPOSED TO -- NOT BE CLERICAL WORKERS

A: We have data from Network #5 and from my observations that Social Workers are the defacto clerical workers in dialysis units. Dialysis units should be made to hire sufficient clerical personal so SWs can do what they are hired to do. They are grossly misused.

(Action Option 35) REQUIRE BEFORE INVOLUNTARY DISCHARGE AN ETHICS CONSULT OR EVALUATION

Many dialysis units do not have access to an ethics committees or an ethics consultant, so I would just encourage that needs to be done.

Q: Were you thinking of an outside consultant, outside the corporation?
R: Or there could be a committee within a corporation, but they would have to have some ethical training.

(Action Option 36) DEVELOP PROCESS MEASURES WHICH CAPTURE THE INTENT TO PROVIDE "INITIAL COMPREHENSIVE PSYCHOSOCIAL EVALUATIONS"

A: This refers to a process to measure and to capture intent of professionals to speak to the comprehensive

psychosocial evaluation that ensures that patients have an appropriate referral to psychiatrist for follow up.

(Action Option 37) ENCOURAGE HOME PROGRAMS AND SELF CARE DIALYSIS SO THAT WE CAN BETTER USE EXISTING RESOURCES

C: Just amen to that.

C: Second amen. I think patients who are involved in their care are going to be able to perform duties that they get so mad at the staff for performing badly.

Q: Does this statement include daily and nocturnal programs?

R: Yes.

Q: Would you entertain an amendment at the end that says that we can utilize existing resources and reducing conflict?

R: I like it the way it is, if we better utilize our resources, it would affect some of these other resources, like lack of staff, like of training and lack of payment.

(Action Option 38) SUPPORT PROPOSED LEGISLATION FOR PREDIALYSIS EDUCATION

A: Does not need explanation

(Action Option 39) CONTINUE DEVELOPMENT OF HOLISTIC, PATIENT-CENTERED DISEASE MANAGEMENT PAYMENT SYSTEMS

We've been very clear that that's the way we want to go. Instead of paying in silos where incentives may not be aligned, we want to align a system that has good process, includes accountability, and some incentive payment that allows innovation to be rewarded if patient outcomes are better.

(Action Option 40) INCLUDE CONFLICT PROBLEMS IN ROUTINE QA & QI PROGRAMS

A: I don't think that facilities know to improve this in routine exam and processes. I want to see this addressed.

(Action Option 41) DEVELOP A MODEL OF PATIENT TERMINATION PROCEDURES THAT INCLUDE NETWORK INVOLVEMENT PRIOR TO DISCHARGE

That was just to make sure that we think about involving networks as part of problem-solving process, instead of just informing them at end after the patient has been discharged.

Q: Just making sure, you're talking about the facility using you as a consult, not having any authority?
R: Right.

(Action Option 42) DEVELOP METHODOLOGY FOR INDEPENDENT DATA TO ASSESS ACCURACY AND RELIABILITY

A: As we move toward patient entry form of data, we will receive and networks will receive data from the national labs. If we get garbage in / garbage out. I want this considered to provide credibility in the community that data received is valid. This would be independent data validation.

C: We would be remiss if we didn't require this.

Q: What do you mean by data, are you referring to behavior reporting, lab reporting?

R: I am referring to any thing used as performance measures that will be used make decisions about our performance.

C: For your information, performance measures in managed care need to be reviewed by auditor from beginning to end. This is one example of an option.

Q: Would you amend this to include valid and reliable?

Valid means truly reported and reliable means the same thing is measured given the same set of circumstances.

Author agreed to amend.

(Action Option 43) ENCOURAGE TRANSPLANTATION AS A BETTER USE OF OUR RESOURCES AS WELL

This could be inserted into #37.

Table 3: List of Action Options and Preliminary Clarification for Addressing the System of Challenges

(Action Option 44) IMPLEMENT AN EDUCATION PROGRAM, LED BY THE NETWORKS, THAT WILL CONTINUOUSLY IDENTIFY AND TRAIN FACILITY STAFF AS CONFLICT RESOLUTION TRAINERS

A: I don't want us to walk away from training trainers. Train them and say goodbye.

Q: Would you entertain including "intermittent", rather than continuous, or "periodic"?

R: No. This is what I mean.

Q: Isn't this similar to item 18?

R: This is an elaboration of item 18.

(Action Option 45) DISSEMINATE THE FINDING AND RECOMMENDATIONS OF THIS WORKSHOP TO THE RENAL COMMUNITY

I just think the things that come from the conference, other people need to know about it, we need other people to weigh in really heavily.

C: Think properly structured, this might be something to submit to AJKD as a special article. Think the paradigms that are put forward here, should be distributed to the renal community and that should be done in a peer-reviewed journal.

R: Actually think of something other than just a journal article here and having other people weigh in.

(Action Option 46) ENCOURAGE THE DEVELOPMENT OF PEER COUNSELING OR MENTORING PROGRAMS FOR PATIENTS

This is clear.

(Action Option 47) ESTABLISH A PAYMENT DIFFERENTIAL FOR THOSE PATIENTS WHO ARE RESOURCE INTENSIVE

Ideal is to have a disease management program that looks across the spectrum, but if we can't do that in the short term, this is a good idea.

APPENDIX F

DELPHI Survey Cover Letter

MEMORANDUM

Date: October 16, 2003

To: Forum of ESRD Networks' Consensus Conference Participants

From: Diane Conaway and Janet Crow

Subject: DELPHI Study and Additional Conference Products

The Facilitation Team would like to thank all of the participants for their extremely hard work, perseverance and good humor during the Dialysis Patient-Provider Conflict (DPPC) Consensus Conference on "Designing A Collaborative Action Plan with the ESRD Stakeholders." The purpose of this document, (which we refer to as a DELPHI Study or questionnaire) is:

- to reflect on our collective and individual learning;
- to further cultivate collective leadership in this initiative;
- to self-identify the perceived roles, with respect to specific actions, appropriate for your organization to engage;
- to offer commentary on the consensus actions to which you are committed; and
- to set the stage to enlarge the number of organizations involved.

The responses to this DELPHI will be integrated with the Final Report. Your responses will also guide near term action. This is the primary vehicle in which you should articulate what you perceive to be your organization's role with respect to this initiative on Designing a Collaborative Action Plan with the ESRD Stakeholders.

In the culminating stage of the Conference, the boundary-spanning teams achieved a super majority (four to five of five teams) on 8 proposed action options. A key finding of the Conference is a unanimous call amongst the small teams of participants to:

- ***Adopt the setting of National curriculum/standard of education for dialysis technicians.*** (Action Option #6 in Cluster #2: Education Standards) which is clarified as meaning:

  A: Author amended statement to include encourage or adopt. There are existing standards that won't cost units anything.
  Q: Would you consider removing encourage?
  Author accepted
  Q: Do you mean uniform national standard?
  R: That would be great but I don't see that happening. A national standard would be great.
  Q: Would you add provide federal reimbursement?
  Amended to include national standard
  C: The term standard means the lowest allowable, not optimal or benchmark.
  Number 17 Clarification was merged with #6
  C: Standards and curriculum are different.
  Item #6 amended to include curriculum

- ***Increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives for DPPC***. (Action Option #11 in Cluster #5: Incentives) which is clarified as meaning:

  I know we've been talking a lot about an important issue, but it's also a narrow issue as far as corporate obligations. We're not just a dialysis provider, we're a healthcare provider. So all of the initiatives that come down from federal government have to be implemented by corporation. A good example of that is HIPAA. Most corporations spent half a million implementing HIPAA. All of the things we're talking about are going to cost money. Interviewed people before I came here, the message was very clear. We're stressed as far as we can. We would like money left over to try to do something about the disease. We're going to have to find a little more money somewhere for much more to be implemented.

  Q: Would you consider adding after increase reimbursement, in keeping with inflation? Because I would suggest that that's been the error since 1973.

  R: I think that would be fine.

  C. That's not necessarily a bad thing, to track capital into the market, shareholders will need to have decent return. We have been sympathetic to increases to get composite rate above water., We have supported and encouraged development of – we believe we should be paying a fair rate for dialysis services that let you be innovative and put in education so you can get best outcomes. If you can help us improve patient care and reduce hospitalization, we'd be more than happy to share that money with you. But just giving more money every year is an easy way out. We need to be smarter and work harder.

- ***Adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility.*** (Action Option #19 in Cluster #9: Prevention/Termination) which is clarified as meaning:

  This is the 600-pound gorilla, are there any questions? The program has been in existence since 1972, when Nixon was president, my hair came down to my shoulders, and we were involved in land war in Asia. Some things never change. I mean, there are detailed regulations that the IRS has and government publications dealing with how much money I can deduct for using my car for business purposes. There is nothing regarding what can essentially be a life and death decision for 360,000 people under this program. There's a disconnect.

  Q: Fascinating and provocative. The question is whether or not for example in spinning this out, I'm not arguing pro or con. My question is does this overlap into becoming a civil rights issue.

  R: Rules are two-edged swords. They establish a minimum standard that you have to meet, but they also establish a cover that if you meet them, you might be presumed to be acting reasonably. It's easier for an industry to take the bull by the horns and attempt to control what happens because if you don't, it's going to be determined by courts and not by the industry.

  Q: Do you mean terminating benefits to a patient or terminating payment to a dialysis facility?
  R: This is strictly about what happens to the patient, rather than consequences for a facility.

  Q: So if a patient were to pull a gun in dialysis unit, that would be reason for Medicare program to stop paying benefits?

  R: No.

  C: There's a difference between terminating treatment and terminating benefits. We have no right to terminate benefits. So maybe you want to put terminating treatment at that facility.

- ***Leverage dialysis units to "make" social workers do what they are supposed to – not be clerical workers***. (Action Option #34 in Cluster #10: Federal Oversight) which is clarified as meaning:

  > *A: We have data from Network #5 and from my observations that Social Workers are the defacto clerical workers in dialysis units. Dialysis units should be made to hire sufficient clerical personal so SWs can do what they are hired to do. They are grossly misused.*

The Conference of October 2 & 3 represents a highly leveraging step towards achieving these ends. The hosts of the Conference, namely the Forum of ESRD Networks, expressed their long-term commitment as well as their desire for collaborative action in launching and implementing the Conference findings and recommendations.

The resulting Consensus Action Scenario appears graphically in Figure 3. This scenario is based on:

(a) A preliminary focus on the four highly leveraging challenges to address, shown at Levels IV and III of Figure 1B. The structure of challenges was completed on Day One of the Conference and appears as Figure 1B in your workbooks. It is also included in the DELPHI package as an Appendix. This structure included every challenge that four or more individuals identified in their top five more important challenges. The influence relationship amongst the challenges was generated by a series of assertions, by the participants, regarding the influence of making progress on one challenge with respect to addressing another challenge. Figure 1B represents a collective judgment on over seventy five decisions determined by the strong majority of two thirds or more of the participants. As you'll recall many of these decisions were nearly unanimous.

(b) The Action Options identified by individual participant selection of the five options of higher relative importance. This resulted in 14 Action Options that received four individual votes or more from the entire group of participants.

(c) The Action Options selected by three or more of the five small teams for inclusion in their team action scenario. This resulted in a focus on 14 Action Options. One Action Options that received 2 team votes were selected for inclusion in the Consensus Action Scenario after deliberations at the plenary session.

Table 7 displays results b and c in a summary form. You will see that the Action Options included in the Consensus Action Scenario and connected to the TIE LINE in Figure 3 are the same fifteen. Table 7 and Figure 3 are for the "Choice" portion of your workbooks.

These fifteen consensus action options are presented in Attachment A for the purpose of asking you to provide additional information on collective leadership in this initiative.

During the Conference we completed a first round of inquiries concerning Definition and Design. The DELPHI Study moves us into the Choice and Action stages of the overall project. This stage of our project should be considered as an opportunity to revisit and reflect on the issues, challenges, opportunities and next steps, the broader set of stakeholders, our individual and collective learning, and your role and leadership on the Forum of ESRD Networks Initiative.

The Forum partners consider it essential to conduct every step of the process in an open and transparent fashion and to reflect the "bottom-up" emergence of focus and collaboration. We realize that this format is unusual for many of you. If you have any questions about the tasks requested, please feel free to contact Diane Conaway at 610-651-0414. Thank you in advance for your help and cooperation in completing this DELPHI questionnaire.

Please fax your responses included in Attachment A and B of the DELPHI Study no later than noon on October 23rd to Janet Crow at 804-378-7351.

Attachment: DELPHI Study

APPENDIX G

DELPHI Survey Responses

DELPHI Responses to Next Steps and Follow-Up Including Leadership Roles on selected Consensus Action Options

(6 - ACTION OPTION): ADOPT THE SETTING OF A NATIONAL CURRICULUM / STANDARD OF EDUCATION FOR DIALYSIS TECHNICIANS

A: Author amended statement to include encourage or adopt. There are existing standards that won't cost units anything.

Q: Would you consider removing encourage? Author accepted

Q: Do you mean uniform national standard? That would be great but I don't see that happening. A national standard would be great.

Q: Would you add provide federal reimbursement? Amended to include national standard

C: The term standard means the lowest allowable, not optimal or benchmark.

Number 17 Clarification was merged with #6. C: Standards and curriculum are different. Item #6 amended to include curriculum

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Conditions for Coverage.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Role: No direct role. Not sure how CRN could be involved in leadership of this initiative – should be NANT. Comments*: No direct involvement but would support via written statement. NANT should take lead with Networks and CMS support.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: Collaborate with NANT on development of education. Comments*: Need to check with ANNA to see what is currently available* *We have done work with NANT in the past – so need to research what has been done previously.* *Support this work by telling members and dialysis units that this is taking place.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: As a patient organization we can offer insight into the problems (perceived & real) that patients face from untrained, staff with no sensitivity training and no consistency throughout the country (or corporations).
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Promoter and provider of educational opportunities. Comments*: Our organization provide educational programs for the benefit of certified technologists. Many techs provide a local certification exam to cut cost for these taking the exam.*
The Forum of ESRD Networks	D. Goldman	Role: Vet for appropriate inclusion of crises management skills. Comments: *1) Develop curriculum. 2) Vet curriculum by stakeholders. 3) Reimburse enough for provision of training OR certify techs. By CMS (Nat'l. Standards).*
Gambro Healthcare U.S.	K. Hall	Role: Supported as individual. Comments: *Implementation required incorporation into new Conditions for Coverage. CMS is control of Medicare Conditions. While this action was very popular with the committee, I believe this is an unlikely outcome. It will not be popular with providers. It will be necessary for CMS to manage this action.*
The Forum of ESRD Networks	G. Harbert	Role: Partner. Comments: *1) Provide input into federal regulations. 2) Work with ANNA/NANT/NRAA/RPA to adopt a curriculum. 3) Consider asking Amgen for support to consider/adopt Core Curriculum for dialysis technicians.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: *Review and promote the use of proposes curriculum/standard.* Comments: *Begin with the compilation of existing documents such as: Amgen Core Curriculum for the Dialysis Technician. It might be possible to adopt an existing curriculum and then develop a national standard of education for Technicians.*
DaVita, Inc.	L. Howard	Role: I would like to be involved with any task force/ committee involved in defining a national curriculum for technicians. Comments*: Need to check with ANNA to see what is currently available.* *We have done work with NANT in the past – so need to research what has been done previously.* *Support this work by telling members and dialysis units that this is taking place.*

(6 - ACTION OPTION): ADOPT THE SETTING OF A NATIONAL CURRICULUM / STANDARD OF EDUCATION FOR DIALYSIS TECHNICIANS (continued)		
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Encourage Networks to provide conflict resolution training for dialysis facilities. Comments: 1) Engage Association for technicians to develop standards and testing. 2) Lobby State legislatures to enact State law to require certification of technicians. 3) Have Networks provide ongoing training in conflict resolution.
Renal Care Group (RCG)	W. Funk Schrag	Comments: *RCG is in the process of developing a standardized curriculum for PCT's so could share some of our experience in developing this.*
Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation	W. Funk Schrag	Comments: *CNNT may want to have input on this. Contact: names provided.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Assure that resources are available to train technicians. Comments: If core standards are developed, then facilities can set up their training accordingly *Some standards have already been adopted in some states. Some of those standards are higher than core standards. Standards could be phased into place.* *The task force used should include physicians, nurses, administrators and technicians.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Comments: *Regulators can support but I don't believe they lobby for change on those they regulate*.
Ethicist (Univ. of Texas)	W. Winslade	Role: Include ethics and interpersonal psychodynamics training. Comments: *This curriculum and standards should NOT deal ONLY with technical issues – the technicians should receive education about the issues that provoke patient-provider conflict and how to deal with them.*

(11 - ACTION OPTION): INCREASE REIMBURSEMENT IN KEEPING WITH INFLATION FOR DIALYSIS SO THAT FINANCIALLY STRETCHED CORPORATIONS CAN IMPLEMENT EDUCATIONAL AND OTHER INITIATIVES FOR DPPC

I know we've been talking a lot about an important issue, but it's also a narrow issue as far as corporate obligations. We're not just a dialysis provider, we're a healthcare provider. So all of the initiatives that come down from federal government have to be implemented by corporation. A good example of that is HIPAA. Most corporations spent half a million implementing HIPAA. All of the things we're talking about are going to cost money. Interviewed people before I came here, the message was very clear. We're stressed as far as we can. We would like money left over to try to do something about the disease. We're going to have to find a little more money somewhere for much more to be implemented.

Q: Would you consider adding after increase reimbursement, in keeping with inflation? Because I would suggest that that's been the error since 1973. R: I think that would be fine.

C. That's not necessarily a bad thing, to attract capital into the market, shareholders will need to have decent return. We have been sympathetic to increases to get composite rate above water., We have supported and encouraged development of – we believe we should be paying a fair rate for dialysis services that let you be innovative and put in education so you can get best outcomes. If you can help us improve patient care and reduce hospitalization, we'd be more than happy to share that money with you. But just giving more money every year is an easy way out. We need to be smarter and work harder.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Advocating for reimbursement that is fair and appropriate for the level of services provided to Medicare beneficiaries. Comments: *This is an issue that cannot be addressed directly by any stakeholder at the conference. Reimbursement for composite rate services is under the preview of Congress.*
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Role: CRN Chairperson has written letters to legislators to support this increase. Comments: *NKF is a member of Kidney Care Partners that supports this legislation. CMS needs to support annual inflation increase for dialysis providers. It is impossible to implement new programs without support and resources.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: We have legislative representatives from each Chapter and Nationally. Comments: *Support legislation. Write in campaigns, etc.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: We (AAKP) have a policy statement on this and frequently discuss additions or modification that need to be made.
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Limited.
The Forum of ESRD Networks	D. Goldman	Role: Support in order to make a business case for quality and decreased conflict. Assist in developing accountability measures to assure that ↑ reimbursement is improving DPPC education and other initiatives. Comments: *CMS acceptance. Congressional lobbying. Develop accountability measures tied to the ↑ reimbursement.*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments*: This is in control of Congress and CMS. Dialysis community has been actively lobbying for this.*
DaVita, Inc.	L. Howard	Comments: *This is essential to move forward any national initiatives – the payors are going to want assurances that increase in reimbursement are spent in ways that will result in progress towards specified initiatives.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Lobby within CMS to increase payment to dialysis facilities. Comments: *1) Provide data to support increase composite rate. 2) National organizations need to lobby Congress to increase the composite rate.*
Renal Care Group (RCG)	W. Funk Schrag	Comments: *RCG is part of Kidney Care Partners and is working to advocate and support this legislation.*

(11 - ACTION OPTION): INCREASE REIMBURSEMENT IN KEEPING WITH INFLATION FOR DIALYSIS SO THAT FINANCIALLY STRETCHED CORPORATIONS CAN IMPLEMENT EDUCATIONAL AND OTHER INITIATIVES FOR DPPC (continued)		
Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation	W. Funk Schrag	Comments: *The NKF public policy office is involved in legislative advocacy for this and is a member of Kidney Care Partners.* Role: Encourage Congress and CMS to increase reimbursement according to inflation.
National Renal Administrators Association (NRAA)	A. Stivers	Comments: *1) In 17 years, our salaries for each staff member has increased 2% to 4% each and every year. This is an average of 51% in 17 years. In addition, staffing mix has changed from all RNs to mostly technicians. The patient load for each staff member has increased from 1:2 to 1:4. We need financial backing. We're stretched as far as we can go. 2) Need a market basket update, not bundling. 3) Work with CMS to develop reasonable reimbursement plan that will provide an opportunity to meet quality and reporting standards.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Comments: *Regulators do not impact funding other than the fact that the citations support the need for more attention to reimbursement.*

(19 - ACTION OPTION): ADOPT COMPREHENSIVE REGULATIONS FOR THE PROCEDURES AND STANDARDS FOR LIMITING AND TERMINATING PATIENT SERVICES AT A FACILITY

This is the 600-pound gorilla, are there any questions? The program has been in existence since 1972, when Nixon was president, my hair came down to my shoulders, and we were involved in land war in Asia. Some things never change. I mean, there are detailed regulations that the IRS has and government publications dealing with how much money I can deduct for using my car for business purposes. There is nothing regarding what can essentially be a life and death decision for 360,000 people under this program. There's a disconnect.

Q: Fascinating and provocative. The question is whether or not for example in spinning this out, I'm not arguing pro or con. My question is does this overlap into becoming a civil rights issue.

R: Rules are two-edged swords. They establish a minimum standard that you have to meet, but they also establish a cover that if you meet them, you might be presumed to be acting reasonably. It's easier for an industry to take the bull by the horns and attempt to control what happens because if you don't, it's going to be determined by courts and not by the industry.

Q: Do you mean terminating benefits to a patient or terminating payment to a dialysis facility? R: This is strictly about what happens to the patient, rather than consequences for a facility.

Q: So if a patient were to pull a gun in dialysis unit, that would be reason for Medicare program to stop paying benefits? R: No.

C: There's a difference between terminating treatment and terminating benefits. We have no right to terminate benefits. So maybe you want to put terminating treatment at that facility.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Conditions for Coverage.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Role: Supportive Comments: *CRN's role is not direct but would support via written statements. Lead role should be via Network, & SW's with feedback from renal community*.
American Nephrology Nurses' Association (ANNA)	E. Colvin	Comments: *I believe ANNA should be a collaborating organization in discussion about this.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: We (AAKP) can meet with CMS and other patient perspective. Educate corporation and CMS on what patients go through emotionally and how this can affect outbursts. Comments: *Prepare a Policy Statement at the next AAKKP Board meeting on what we recommend should be allowable.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Limited.
The Forum of ESRD Networks	D. Goldman	Role: Advising CMS. Collecting, validating, interpreting data. Comments: *CMS is in the driver's seat.*
Gambro Healthcare U.S.	K. Hall	Role: Support, assist with regulatory language. Comments: *Again, requires action from CMS.*
The Forum of ESRD Networks	G. Harbert	Role: Partner. Comments: *1) Assemble legal/ethic group to explore issue from both perspectives and produce position paper. 2) Work with stakeholders to develop consensus/buy-in for position paper regarding appropriate/inappropriate termination form facility. 3) Provide input into development of federal regulations upon 1 & 2. This is influenced by the Entitlement question.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Working closely with the DPPC group to draft a proposed regulation for submission to CMS for consideration. Comments: *This might not be a task that can be accomplished easily. It would need to be written swiftly to have a chance to make it into the Conditions for Coverage. Using some of the data from the NW 11 Involuntary Patient Discharge Project and NW 17s consensus conference language may help move the process more quickly. Introducing and using a common language/taxonomy is essentials, so perhaps using it in a regulatory document would be a good opportunity.*

(19 - ACTION OPTION): ADOPT COMPREHENSIVE REGULATIONS FOR THE PROCEDURES AND STANDARDS FOR LIMITING AND TERMINATING PATIENT SERVICES AT A FACILITY (continued)		
Psychologists, Washington University	B. Hong	Role: Act as consultant. Comments: *Would facilities use them if available? Would the goal be to develop a model set of regulations?*
DaVita, Inc.	L. Howard	Role: I would like to be involved in developing a framework for guiding facilities through the process of limiting/terminating dialysis services. Comments: *This is an important area. There are some clear instances where the decision to treat or not to treat are fairly easy, i.e. patients bringing weapons to the clinic. However, it is important to appreciate the "slippery slope" to providing healthcare to the "saints" but not to the "sinners".*
ESRD Network Patient Services Coordinators	M. Meier	Role: Assist a workgroup in the development of language to meet the action option. Comments: *This issue belongs in the ESRD regulations. However, a workgroup might be able to craft guidelines which could be sent to CMS during the formal comment period when the regulations are released.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Comments: *I do not agree that a patient's benefits should be terminated once they are entitled under the law. The national dialysis corporations, organizations representing smaller chains and independent facilities and Networks should discuss how to limit conflict in the facilities while protecting the patient's rights. If a patient is harmful to other patients or staff, the patient should be dismissed from the facility but should not have benefits terminated because then they would not be able to obtain treatment at an alternate facility/institution.*
Renal Care Group (RCG)	W. Funk Schrag	Comments: *Dialysis facilities/chains and networks may be able to work on this together from already existing terminating services, policies and procedures.*
Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation	W. Funk Schrag	Comments: *NKF Patient and Family Council. Contact name provided.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Communicating to physicians staff and patients about the new regulations would like to work on. Comments: *1) I'm encouraged about creating a regulation that cannot be implemented in all cases, i.e. areas where there is only one facility. It could literally end up being a death sentence for a patient. 2) I am more for guidelines unless regulations also have solutions for treating the patient that is terminated. 3) Mediation from an outside source should be part of the procedure. 4) Should include a panel that determines termination but should have time frames. 5) Termination should be identified in steps. Except gun. Terminate that day. Abusive have – warning. 6) Prior to implementation of regulation – get input from renal community.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Role: Participate in developing regulation. Comments: *This should be encompassed in a patient's rights condition of participation.*
Ethicist (Univ. of Texas)	W. Winslade	Role: Critique the ethical and legal regulations. Comments: *This topic requires careful analysis of issues as well as underlying and often unstated biases and prejudices.*

(34 - ACTION OPTION): LEVERAGE DIALYSIS UNITS TO "MAKE" SOCIAL WORKERS DO WHAT THEY'RE SUPPOSED TO -- NOT BE CLERICAL WORKERS

A: We have data from Network #5 and from my observations that Social Workers are the defacto clerical workers in dialysis units. Dialysis units should be made to hire sufficient clerical personal so SWs can do what they are hired to do. They are grossly misused.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Conditions for Coverage.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *This needs to be more clearly defined. SW group should develop practice guidelines and obtain Network support*.
American Nephrology Nurses' Association (ANNA)	E. Colvin	Comments: *We could support this imitative. Need to be explored.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: A Policy Statement from AAKP or recommendation.
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Support.
The Forum of ESRD Networks	D. Goldman	Role: Support ↑ reimbursement tied to social worker outcomes / performance. Comments: *CMS must support.*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *Again, this action rests mainly on CMS and new Conditions for Coverage. Education provided by networks to community may be helpful.*
The Forum of ESRD Networks	G. Harbert	Role: Support. Comments: *This is largely controlled by the corporations. I am not sure how to influence this short of regulation. SW's are discontented with assigned role but not empowered to change under current job descriptions and employment agreements. CNSW could lead an effort. CMS could regulate.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Supportive of SWs. Comments: *The Patient Service Coordinators, Dialysis Corporations and NASW/CNSW groups would best serve this option.*
ESRD Network Patient Services Coordinators	M. Meier	Role: Provide leadership in defining the "appropriate" use of MSW's. Comments: *It would be important to collaborate with the CNSW to define and agree to what it is MSW's "should b" doing. Again it will be necessary to partner with CMS to have this in the regulations.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Reduce reporting burden. Comments: *CMS has taken an active role in reducing paperwork burden in facilities. This should free up some of their time to devote to patients.*
Renal Care Group (RCG)	W. Funk Schrag	Comments: *RCG has a Social Work Advisory Board that could provide input on this.*
Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation	W. Funk Schrag	Comments: *CNSW would be interested in being involved with this.*

(34 - ACTION OPTION): LEVERAGE DIALYSIS UNITS TO "MAKE" SOCIAL WORKERS DO WHAT THEY'RE SUPPOSED TO -- NOT BE CLERICAL WORKERS (continued)		
National Renal Administrators Association (NRAA)	A. Stivers	Role: Assure there is support for SW and that SW can do what sub-part 4 requires. Comments: *I object to the word "make". In small units of 20 or less patients or even 50 or less, I believe it is ok that duties include additional tasks that may not always be in the duties of a large unit. I am for the leverage in larger units where patient population exceeds 100. Not all SW want to be included in conflict management nor know how to manage conflict.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Role: Suggest survey include probes to see that social worker is utilized. Comments: *Review new regulations to see where this fits.*

(2 - ACTION OPTION): HAVE THE NETWORKS AND/OR NIH AND/OR USRDS PROVIDE / INVENT A DATA GATHERING TOOL TO AID DATA COLLECTION AND METHODOLOGY

A: Are there any questions about this?

Q: Do you think the networks can do this? R: Usually the work flows from NIH to the network.

Q: Do you need to put "and or" in the statement? R: Statement was amended

Q: There is a current program called Client Performance Measures project that correlates databases. Is what you are proposing in addition to that?

R: Yes. This is a separate data-gathering project that would clarify and define the issue.

Q: Does the "and or" go between networks and NIH? R: Yes.

C: In the core data set we will be working on this. CPS are population and these are specific. The data will be reported back to the networks. This will be brought into the data issue. Don't know if we want to bring both into this. We want to get this done quickly.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Core Data Set.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *Network function*.
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: We could provide input and encourage units to participate.
Information Infrastructure Workgroup (subcommittee of the Forum Board of Directors)	C. Dunnagan	Role: We can leverage some elements that will be collected as part of the average data set to gather this information. We also have the ability to work quickly and efficiently with the large provider organizations to help find answers.
America Association of Kidney Patients (AAKP)	B. Dyson	Role: Work with whoever decides to undertake the task (maybe CMS) to look at what needs to be collected, etc.
Network Executive Directors	B. Freed	Role: Leadership. Comments: *Networks would gather, analyze and report data, therefore, would plan an important role in developing the tool and in this collection process.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Support.
The Forum of ESRD Networks	D. Goldman	Role: Networks input into vision. Comments: *This is ongoing work already being done – DPPC must have more and/or improved data fields.*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *This needs to be incorporated into electronic data gathering by CMS in some manner. There is great resistance among providers to additional data gathering. Corporations feel data gathering and submission is extremely burdensome.*
The Forum of ESRD Networks	G. Harbert	Role: Lead/partner. Comments: *1) Work in NW pilot project. 2) Support development. 3) Co-chair workgroup to adopt NW 17 taxonomy.*

(2 - ACTION OPTION): HAVE THE NETWORKS AND/OR NIH AND/OR USRDS PROVIDE / INVENT A DATA GATHERING TOOL TO AID DATA COLLECTION AND METHODOLOGY (continued)		
ESRD Network Quality Improvement Directors	L. Hegel	Role: Participate on a workgroup to facilitate the development and definition of a data collection mechanism. Comments: *Review current data streams as a possible starting point such as: the Multi-NW Involuntary Patient Discharge Project.* *Examine the potential for incorporation into VISION or SMS or Core Data Set.*
Psychologists, Washington University	B. Hong	Comments: *NIH funds research, it will not develop tools or recommend them. Another agency if the federal government would be more appropriate.*
DaVita, Inc.	L. Howard	Role: I would like to be involved in the development of data collection tools. Comments: *This is essential if we can't define the problem and the drivers behind it, our "solutions" are guesses.*
ESRD Network Patient Services Coordinators	M. Meier	Role: Assist with the development of a taxonomy of terms. Comments: *The development and agreement upon methodology is essential in order to begin collecting data on this issue.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Fund NW special projects. Comments: *The Networks can collect the minimum data necessary to be able to report on noncompliant / threatening patients. CMS has already funded NW 17 to develop a dictionary to describe patient behaviors. The next step is to test if these descriptions will help the facilities to describe problems. In additions the NWs are already working on what data they will need to collect to report on the magnitude of the problem.*
National Renal Administrators Association (NRAA)	A. Stivers	Comments: *If needed provide information that may be needed.*

(14 - ACTION OPTION): INCREASE AND COORDINATE FEDERAL QA & QI ACTIVITIES

A: The regulations are useless if they are not enforced. We have a resource in the ESRD networks to help facilities. We want them to help clinics, and independent providers involved. Many of them don't know how to do QI. They need additional resources to fix things before state surveyors come in. It is better to fix a problem before a problem. We don't want to shut them down. The ramifications are disturbing. We need to get the networks and state surveyors working together. This would be a better approach Federal improvements take time.

C: One hazard in a uniform approach is that what we collect analyze.

R: Yes.

Q: All facilities say they have QA or QI but don't address these problems specifically. Do we want to add language that focuses on this particular problem?

R: No, this is just our oversight of the program in general.

Q: Can we add language that speaks to getting this problem included? Group decided to propose new item 40.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Leadership. Office of Inspector General and General Accounting Office have noted CMS could a better job of coordinating QA & QI roles.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *Networks perform this function currently.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: We are currently very active in development. Supporting & QA activities.
America Association of Kidney Patients (AAKP)	B. Dyson	Role: Add the patient perspective.
Network Executive Directors	B. Freed	Role: Partner and/or support. Comments: *Networks could provide assistance in developing federal QI plans based on the results of the data collection.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Limited.
The Forum of ESRD Networks	D. Goldman	Role: Coordinate – yes "enforce" is troubling.
Gambro Healthcare U.S.	K. Hall	Comments: *This item needs clarification. It initially speaks to facilities not knowing how and not having resources. It then refers to Federal QA and QI activities. It is not clear what the focus of the action option is.*
The Forum of ESRD Networks	G. Harbert	Role: Support. Comments: *Must be driven by CMS.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Participate in the development of sample QI/QA initiatives for inclusion in facility QI Programs. Comments: *Assemble workgroup to design templates. National roll-out that could include required data collection. Regional training of Social Workers regarding incorporating this type of AQ into their area.*
Psychologists, Washington University	B. Hong	Comments: *QA programs need to directly include material addressed to the psychosocial problems of patients and provider/patient communication.*

(14 - ACTION OPTION): INCREASE AND COORDINATE FEDERAL QA & QI ACTIVITIES (continued)		
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	**Role:** Have Networks back facilities how to do QA & QI. Fund development of QA/QI tool box. **Comments:** *1) Identify exactly what we want NWs to do. 2) Have a uniform program developed including a QA/QI tool box for facilities. 3) Have NWs teach facilities and do QA/QI.*
National Renal Administrators Association (NRAA)	A. Stivers	**Role:** Give input as requested. **Comments:** *1) QA & QI difference is still not completely understood in all units. 2) Before increasing regulations, coordinate the information now provided. 3) Assure that information now provided is reported in timely manner before moving to an increase in QA activities on federal level.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	**Role:** Continue to identify deficient practices in this area.

(16 - ACTION OPTION): REQUIRE FACILITIES TO REPORT INVOLUNTARY DISCHARGES TO THE NETWORK

A: The data that networks collect does not currently include lost or follow up. There is no mechanism to gather involuntary discharges. There should be a mechanism to include this on an individual basis. When they occur have a phone call

C: We have a workgroup in the network working on this. We are developing a broad definition for but it does not include a call to the PSD.

Q: would you add to your statement, wording that gets to networks not just reporting but involvement and reporting to networks so they are involved in process?

A: For clarity, I will leave as is.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Conditions for Coverage.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *CRN does not have direct role but support this action. Network function.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Comments: *Support this idea.*
Information Infrastructure Workgroup (subcommittee of the Forum Board of Directors)	C. Dunnagan	Comments: *Core data set elements will contribute to the collection of this data. The data should be available starting with the spring release of the crown software applications.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: A wonderful first step. It needs to be mandatory.
Network Executive Directors	B. Freed	Role: Partner. Comments: *The regulation would need to be from CMS but once that was in place Networks could take an active role in working with facilities to see that the reports were completed.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Limited.
The Forum of ESRD Networks	D. Goldman	Role: Continue data collection and develop new data. Develop tools and other interventions Comments: *Develop and disseminate a tool kit for facilities to assist with conflict management.*
Gambro Healthcare U.S.	K. Hall	Comments: *We need to know the number of patients discharged and circumstances of discharge. Additionally, having to report to the networks may serve as a deterrent to discharge.*
The Forum of ESRD Networks	G. Harbert	Role: Partner. Comments: *1) Work on taxonomy as in Option 2. Educate providers.*
ESRD Network Quality Improvement Directors	L Hegel	Role: Work closely with CMS and SIMS to include these data. Comments: *Add these data to the Patient Rosters as required reporting.*
Psychologists, Washington University	B. Hong	Role: Has a real research potential. Can be a consultant. Comments: *Looking at the "putative" reason for discharge will be highly informative.*
DaVita, Inc.	L. Howard	Comments: *This fits with overall data collection.*

(16 - ACTION OPTION): REQUIRE FACILITIES TO REPORT INVOLUNTARY DISCHARGES TO THE NETWORK (continued)		
ESRD Network Patient Services Coordinators	M. Meier	Role: Work with the core data set developers to define the parameters of "Involuntary Discharge".
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Make sure this collection is included in SIMS. Comments: *The Networks are already working to incorporate capturing involuntary discharges in SIMS.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Report to Network. Comments: *1) This is critical aspect of action. Without data, cannot attach problem. 2) Discharge data should include reasons why discharged. 3) Isn't this already required?* .

DELPHI Responses to Next Steps and Follow-Up Including Leadership Roles on selected Consensus Action Options

(22 - ACTION OPTION): DEVELOP A TASK FORCE TO WORK ON THE DPPC RESEARCH PLAN AND ENUMERATE THE VARIABLES OF INTEREST AND THE ISSUES TO BE STUDIED
A: This is one of the next steps to help put together this plan.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Help with realistic timelines and activities *Comments: Would like to involve Teresa Casey, from CMS for this task force.*
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *CRN would be willing to have a member as one of task force members.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Comments*: If ANNA supports further involvement.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: However needed.
Network Executive Directors	B. Freed	Role: Partner or participate. Comments: *Networks would directly with facilities and patients and would be key in being a member of this task force.*
Gambro Healthcare U.S.	K. Hall	Role: Would be willing to be on task force.
The Forum of ESRD Networks	G. Harbert	Role: Support. Comments: *NW's are prohibited from conducting research.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Representation on a task force. Comments: *Assure that quality issues and considerations are included from the beginning.*
Psychologists, Washington University	B. Hong	Role: Task force member. Comments: *This task is fundamental to real change.*
DaVita, Inc.	L. Howard	Role: This is an area where I would like to be involved. Comments: *Part of data collection.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Assist in funding the task force expenses. Comments: *The task force should represent all types of dialysis facilities since the issues need to be identified and prioritized.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Assist as requested. Comments: *Assure task force includes all disciplines and a consumer.*

(3 - ACTION OPTION): CLARIFY AND CODIFY THE RIGHTS AND OBLIGATIONS OF PROVIDERS AND PATIENTS WHO OPERATE WITHIN AN ENTITLEMENT SYSTEM

I think there was a fair amount of discussion yesterday about what exactly an entitlement program is. I think we are one and this is simply a suggestion for all of us who operate in system, including patients, to understand what this means, legal or otherwise.

Q: By codify, do you mean new legislation, conditions of coverage, federal standards…

R: To me, it means to lay out in clear language, not interpretable for the region or state. I'm just asking in layman's language what does this mean.

C: Now you know clearness and codify are two mutually exclusive things.

Q: Do you mean like a provider and patient's bill of rights?

R: Not only rights and responsibilities, but a very brief and concise statement of what the program is. This is ESRD, this is what it means to patients and providers. More than a bill of rights, it would have… I don't know exactly what I mean. It would not be subject to local interpretation. This is a federal program.

Q: So you're talking about federal interpretation of current entitlement laws? R: I think since I and everyone else here pay taxes for it, yeah.

Q: A simple English interpretation? R: Yeah.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Conditions for Coverage.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Role: CRN would not have lead role. Comments: *CRN would participate and give feedback to group that leads this process.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: However needed.
The Forum of ESRD Networks	G. Harbert	Role: Partner. Comments: *Work with legal/ethical workgroup as in Option 19.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: CMS could provide presentations at national meetings to explain in clear English the laws and regulations governing entitlement and terminations.
National Renal Administrators Association (NRAA)	A. Stivers	Comments: *Needs to be in bold on patient rights and responsibilities.*
Ethicist (Univ. of Texas)	W. Winslade	Role: Clarify legal, ethical and policy issues. Comments: *Caution: even clear statements need to be interpreted and applied to concrete situation in a specific context. It is important not to think that abstract rules and rights can answer questions that arise in particular settings without attention to contextual nuances.*

(4 - ACTION OPTION): UTILIZE THE NETWORK #17 WORKING GLOSSARY AS A STARTING TAXONOMY FOR DATA COLLECTION FOR DPPC

A: This work that network 17 and 18 did was funded by CMS and is good foundation for this (see info in notebook). Before defining methodology we need taxonomy to describe the situation. Since work has been done, this would jumpstart what we are doing.

Q: Could you use this as a start for a working document? R: Yes.

C: These are nice descriptive glossaries but don't replace formal psychiatric diagnosis. You could use this descriptively but need formal documents. In the work done in 11 and 14 the survey indicated a lot of problems using psychiatric terms. Fear of labeling patients by someone who is not qualified to do this.

Not saying you can't proceed this way, there are real pitfalls to doing this you may won't someone qualified. Regarding adequate treatment if you don't do that you cut off from Mental Health services… We're not talking about diagnosis

Q: I agree. Psychiatric evaluations when a situation happen in the unit, people are looking for behaviors, psychiatric evaluations come later. If patient is abusive they are forget why the behavior is there.

Q: Can we offer changes to statement?

Include suggestion about DSM 4 in, DSM 4 diagnosis,

The only thing network 35 did that I take exception to is the term nonconformity connotes molding of patients in preconceived way were non adherence

Statement amended

If we go beyond characterizing actions and labeling patients it becomes an ADA issue. Don't want networks getting into this. Cautioning against this.

I think the glossary is helpful this would be a nice way to get idea of what's going on. Need a clinical psychiatrist to make diagnosis.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Comments: *CMS project approved.*
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *Already available so networks should lead this process/action.*
Information Infrastructure Workgroup (subcommittee of the Forum Board of Directors)	C. Dunnagan	Comments: *We could incorporate these definitions into the existing contacts modules of SIMS and add them to the SIMS contact module user guide.*
Network Executive Directors	B. Freed	Role: Network 17 has completed this.
The Forum of ESRD Networks	D. Goldman	Role: Apply the glossary to data collection and tool development. Comments: *Disseminate glossary to all NW's and facilities. Post on CMS, Forum and NW websites. Use it – refer to it.*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *It is appropriate to utilize existing tools.*
The Forum of ESRD Networks	G. Harbert	Role: Lead/partner. Comments: *Co-chair workgroup to review & achieve consensus among stakeholders.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Support for utilizing the glossary as a starting point.
Psychologists, Washington University	B. Hong	Comments: *This is only one step to a two-step process. Once a DPPC problem is identified, what solutions are open to the staff and when are mental health specialists drawn into the picture.*

(4 - ACTION OPTION): UTILIZE THE NETWORK #17 WORKING GLOSSARY AS A STARTING TAXONOMY FOR DATA COLLECTION FOR DPPC (continued)		
DaVita, Inc.	L. Howard	Comments: *A common language is essential for meaningful data collection.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Fund a special study to test the usefulness of the definitions in the facility setting. Comments: *We are currently working with Network 17 to develop a study to test the usefulness of these definitions.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Would like to help. Comments: *Don't reinvent wheel but may need to adjust.*

(8 - ACTION OPTION): DEVELOP AN ALGORITHM FOR DETERMINING THE LEVEL OF DISRUPTIVE PATIENTS

A: Develop something that will help the staff determine what level of disruption it is, i.e. yelling, medium: yelling and profanities severe: striking out.

Organization:	Workshop Participant:	Perceived Role & Comments:
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Role: CRN would volunteer member to participate on task force.
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: Participate in review of this.
America Association of Kidney Patients (AAKP)	B. Dyson	Role: However needed. Present the patient's point of view.
Network Executive Directors	B. Freed	Role: Partner. Comments: *Networks would be a good partner with other organizations to develop discrete classification and use the algorithm as a facility tool based on these classifications.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Support.
The Forum of ESRD Networks	D. Goldman	Role: Apply the glossary. Collaborate developing algorithm. Comments: *Review literature. Convene experts. Develop evidence based guideline / algorithm. Implement it (implementation plan).*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *Networks could do this and distribute to facilities.*
The Forum of ESRD Networks	G. Harbert	Role: Leadership. Comments: *Engage NW PSC's to draft/develop.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Participate in the development of the algorithm.
DaVita, Inc.	L. Howard	Comments: *Part of data collection.*
ESRD Network Patient Services Coordinators	M. Meier	Role: Assist in the research and development of the algorithm. Comments: *This algorithm would be a useful tool in assisting facility staff as they deal with challenging patient situations.*
Renal Care Group (RCG)	W. Funk Schrag	Comments: *RCG has a policy on violent/disruptive policies that addresses levels of disruption from mild → severe.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Would like to help develop. Comments: *Task force should develop.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Comments: *Should look into why patients are disruptive. Could it be the quality or care they are receiving.*
Ethicist (Univ. of Texas)	W. Winslade	Role: Help clarify the terminology.

DELPHI Responses to Next Steps and Follow-Up Including Leadership Roles on selected Consensus Action Options

(28 - ACTION OPTION): MAKE A BUSINESS CASE FOR IMPLEMENTING THE OPTIONS WE SEE HERE TODAY IN ORDER TO ENGAGE CORPORATIONS AND STAND ALONE DIALYSIS UNITS IN IMPLEMENTING THESE CHANGES

A: We need to go through these we should develop a cost benefit analysis to see if these proposals will lead to a cost savings, if it will be costly and will be a long-term benefit. We should determine if we solve this as a business proposal.

Q: Would this include analysis of results of data collection that we talked about?

R: Whatever projects or solutions we generate today we should include in that a business analysis.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Comments: *Any regulatory change that increases provider burden needs to have a foundation in improving care and/or encouraging efficiency.*
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *Agree, should be done. CRN would not be lead role in this process.*
Network Executive Directors	B. Freed	Role: Partner/ participate. Comments: *Networks could take an active role in bringing appropriate organizations together, i.e. dialysis corporations and possibly MBA programs that might develop such a proposal as one of their master's prepared case studies.*
The Forum of ESRD Networks	D. Goldman	Comments: *Make cash flow assumptions. Achieve consensus on cash flow assumptions (stakeholders). "Crunch" the numbers. If business case is negative, regulatory changes will be required.*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *It is crucial to get buy-in from corporations. Even without data there are cost benefits in avoiding patient conflict. Some of this could be education, i.e., facilities should start with admission of patient to avoid conflicts rather than just reacting.*
The Forum of ESRD Networks	G. Harbert	Role: Support. Comments: *This needs to be accomplished by stakeholders from the business side of the industry.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Help develop the business as based on the cost of poor quality, risk management issues, etc.
Psychologists, Washington University	B. Hong	Comments: *Ask business what outcome measures would they think is relevant?*
DaVita, Inc.	L. Howard	Comments: *This I see as a product coming out of data collection. When we can identify the drivers behind patient "non-compliance" we can identify actions that can be taken to increase patient compliance, improve outcomes, decrease morbidity and mortality and increase treatments.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Would like to help develop. Comments: *Assure that case reflects financial impact on facilities. Assure that case reflects resources used or not used and how it impacts bottom line.*

(40 - ACTION OPTION):INCLUDE CONFLICT PROBLEMS IN ROUTINE QA & QI PROGRAMS
A: I don't think that facilities know to improve this in routine exam and processes. I want to see this.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Conditions for Coverage.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *Agree, input, however CRN would not have lead role in this action. Requires SW & Network collaboration.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: We can encourage this.
America Association of Kidney Patients (AAKP)	B. Dyson	Role: However needed.
Network Executive Directors	B. Freed	Role: Leadership. Comments: *Networks could provide assistance to facilities to develop QI plans based on the results of the data collection to identify both facility and patient specific needs.*
The Forum of ESRD Networks	D. Goldman	Role: Develop a process analysis for conflict resolution. Comments: *Literature review. Develop evidence based process analysis. Encourage QI projects of this subject. Encourage NW QIP's to include conflict management.*
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *Perhaps this should be in new Conditions for Coverage. Also, educational measures with corporations and clinics.*
The Forum of ESRD Networks	G. Harbert	Role: Leadership. Comments: *1) Develop model agenda's. 2) Educate providers. 3) Provide input into federal regulations.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Participate in the development of sample QI/QA initiatives for inclusion in facility QI Programs. Comments: *Assemble workgroup to design templates. National rollout that could include required data collection. Regional training of Social Workers regarding incorporating this type of AQ into their area.*
Centers for Medicare & Medicaid Services (CMS)	I Sarsitis	Role: Have Networks back facilities how to do QA & QI. Fund development of QA/QI toolbox. Comments: *1) Identify exactly what we want NWs to do. 2) Have a uniform program developed including a QA/QI toolbox for facilities. 3) Have NWs teach facilities and do QA/QI.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Assure implementation and program on doing it. Comments: *Develop plan to assure that facilities know how to improve the conflict resolution process.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Role: Verifying whether these are in place, if it is a problem, it should be addressed.
Ethicist (Univ. of Texas)	W. Winslade	Comments: *This is an important item.*

(45 - ACTION OPTION): DISSEMINATE THE FINDING AND RECOMMENDATIONS OF THIS WORKSHOP TO THE RENAL COMMUNITY

I just think the things that come from the conference, other people need to know about it, we need other people to weigh in really heavily.

C: Think properly structured, this might be something to submit to AJKD as a special article. Think the paradigms that are put forward here, should be distributed to the r I just think the things that come from the conference, other people need to know about it, we need other people to weigh in really heavily.

C: Think properly structured, this might be something to submit to AJKD as a special article. Think the paradigms that are put forward here, should be distributed to the renal community and that should be done in a peer-reviewed journal. R: Actually think of something other than just a journal article here and having other people weigh in.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Role: Will discuss in ongoing presentation but inside and outside of government.
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *CRN would share information with members.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: Will inform ANNA of what occurred. Comments: *I have been able to write a summary of this ??? recommendations. Share with the Board, ANNA & though our publications.*
Network Executive Directors	B. Freed	Role: Partner to disseminate the information. Comments: *Develop a paper to outline the results. This would provide consistency in reporting. Networks could share this information through their meetings, newsletters, and one on one communication with facilities' staff and physicians.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Encourage individuals to support recommendations of group.
The Forum of ESRD Networks	D. Goldman	Role: Organize authors. Editorial role.
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *Articles in Kidney journals and other publications.*
The Forum of ESRD Networks	G. Harbert	Role: Partner. Comments: *1) Disseminate the information using NW communication vehicles. 2) Speak at Nat'l. meetings. 3) Support manuscript development.*
Psychologists, Washington University	B. Hong	Role: Group member. Comments: *This is a crucial activity to change the field and to model how Medicare needs to deal with intrusive chronic illness treatment.*
DaVita, Inc.	L. Howard	Role: I would like to be involved in this area as well. Communication on an ongoing basis for the ESRD community will be important to the success of the project.
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: Review what will be said about the conference. Comments: *I think a group should develop a uniform presentation on the results of this conference so the same messages are disseminated.*
Renal Care Group (RCG)	W. Funk Schrag	Role: Disseminate throughout our organization.
National Renal Administrators Association (NRAA)	A Stivers	Role: Assure information provided to renal administrators. Comments: *1) Provide workshops for administrators. 2)CMS should be available at workshops to either present or to answer questions regarding regulation.*

(21 - ACTION OPTION): DEVELOP A SIMPLE BROCHURE OUTLINING THE BASIC TENETS OF CRISIS INTERVENTION AND CONFLICT MANAGEMENT
With relatively little work, this group I think could develop a quick brochure. With relatively little work and some additional funding, this could be quickly distributed and put in the hands of clinical providers.

Organization:	Workshop Participant:	Perceived Role & Comments:
Centers for Medicare & Medicaid Services (CMS)	B. Augustine	Comments: *CMS could sponsor the development of this brochure and distribute it through the ESRD Networks.*
Council on Renal Nutrition (CRN) of the National Kidney Foundation	D. Benner	Comments: *Agree. SW group should have lead role. CRN would participate in group and give feedback.*
American Nephrology Nurses' Association (ANNA)	E. Colvin	Role: Collaborate with work group. Comments: *Present information to our Board at ANNA, and distribute to members/units if acceptable. Provide training at national / local meeting.*
America Association of Kidney Patients (AAKP)	B. Dyson	Role: Will work closely with the Networks and PSCs to get this done.
Network Executive Directors	B. Freed	Role: Partner. Comments: *Include input from large disciplinary groups, not restricted to renal groups. One sug. was the NASW.*
National Association for Nephrology Technicians/Technologies (NANT)	C. Glynn	Role: Support.
Gambro Healthcare U.S.	K. Hall	Role: Support. Comments: *Network's Project*.
The Forum of ESRD Networks	G. Harbert	Role: Leadership. Comments: *Approach CMS to fund brochures developed by NW PSC's.*
ESRD Network Quality Improvement Directors	L. Hegel	Role: Participate by either offering suggestions to include in the brochure or review of draft/final document or both.
Psychologists, Washington University	B. Hong	Role: Consultant.
DaVita, Inc.	L. Howard	Comments: *My sense from talking to several people at the meeting is that there were individuals who could make this happen very rapidly – this would tie in with Action Option #45.*
ESRD Network Patient Services Coordinators	M. Meier	Role: Lead a workgroup to develop. Comments: *The Patient Services Coordinators of the ESRD Networks have a great deal of experience, knowledge, and understanding on crisis intervention and conflict management. This group would be willing to partner with the DPPC workgroup to achieve this action option.*
Centers for Medicare & Medicaid Services (CMS)	I. Sarsitis	Role: After the brochure has been developed, assist in the funding of brochure so NWs can distribute it.
Renal Care Group (RCG)	W. Funk Schrag	Comments: *Could work on this in conjunction with Network staff.*
National Renal Administrators Association (NRAA)	A. Stivers	Role: Assist as requested. Comments: *1) Would be helpful to have a brochure that addresses different techniques or processes for different types of conflict. 2) Make sure brochure addresses different types of conflict and describes meaning.*
Association of Health Facility Survey Agencies (AHFSA)	C. Stokes	Comments: *The providers need more than a brochure.*

APPENDIX H

Bibliography Relevant to the Methodology

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Bibliography Relevant to the Methodology

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