



NKDEP Dialysis Center Working Group Meeting Minutes January 10, 2006

Attendees

- Mark Meier, Renal Network of the Upper Midwest, *Working Group Chair*
- Amy Bogan, DaVita, Inc.
- Teri Browne, Council of Nephrology Social Workers, National Kidney Foundation
- Ann Compton, American Nephrology Nurses' Association
- Dave Fracalossy, National Association of Nephrology Technicians and Technologists
- Elisa Gladstone, NKDEP Associate Director
- Peter Hayden, Turning Point, Inc.
- Amy Hubler, Fresenius Medical Care North America
- Wendy Jagusch, Center for Dialysis Care
- Geli King-Brown, Forum of ESRD Networks
- Nina Kolbe, American Dietetic Association
- Larra Petersen, Mayo Clinic
- Sandra Quinn, University of Pittsburgh
- Karen Toll, NKDEP staff

Welcome and Introductions

- Mark Meier opened the meeting with an overview of the Dialysis Center Working Group (DWG). The goal is to help engage dialysis patients as ambassadors to people at risk for chronic kidney disease (CKD). He noted that there are significant racial disparities in end-stage renal disease (ESRD) and stressed the importance of finding ways to address these. In addition to using existing NKDEP materials, he invited the group to think about additional materials or other assistance NKDEP can provide.

Overview of NKDEP

- Elisa Gladstone provided an overview of the National Kidney Disease Education Program (NKDEP). The program was started about four years ago to improve the early diagnosis and treatment of CKD. She outlined some statistics and facts to illustrate the scope of the challenge:
 - There has been a dramatic increase in ESRD over the past two decades, and an estimated 20 million Americans have CKD, with diabetes and hypertension being the two leading causes.
 - The risk of ESRD is not uniform: African Americans, Hispanic Americans and Asian Americans have significantly higher rates of ESRD than Caucasians.
 - The annual cost of kidney failure (\$25.2 billion).
 - CKD is not being recognized or treated: fewer than 20 percent of Medicare patients with diabetes are screened for CKD, and only one-third with identified CKD are taking ACE inhibitors.

- In 2003, 81 percent of diabetes patients received recommended HbA1C tests, while only 21 percent received recommended microalbuminuria tests.
- Many physicians underdiagnose CKD due to misinterpretation of creatinine values.
- Early detection and treatment of CKD can delay ESRD by as much as seven years, in some cases even halting the progression of the disease.
- Elisa provided an overview of the NKDEP's main objectives, target audiences, approach, history and key messages, and resources for the public and healthcare providers. She also outlined the NKDEP structure, noting that the DWG is one of three current NKDEP working groups – the others being the Evaluation Working Group and Laboratory Working Group.
- Discussion about NKDEP overview:
 - .Mark noted that whereas ESRD patients comprise a very small percent of the all Medicare beneficiaries (less than 1%), they account for nearly 6% of all Medicare expenditures.
 - Wendy Jagush asked about how the NKDEP works with the NDEP. Elisa noted that the two programs collaborate closely.
 - Amy Bogan asked if the NKDEP is seeking legislation to support Federal reimbursement for CKD education activities. Elisa explained that there are restrictions on lobbying by Federal programs. Ann Compton noted that the National Kidney Foundation and others are pursuing this on their own.

History of Dialysis Center Materials

- Elisa then provided an overview of the NKDEP's work with dialysis patients to date.
 - Rationale: various studies show a very low level of awareness that family history is a risk factor for CKD and that ESRD patients (and the dialysis clinics and other organizations) could be engaged as ambassadors to raise awareness.
 - Campaign: Help your Family Prevent Kidney Failure, which asks ESRD patients to educate their family about CKD and encourage them to get tested.
 - Materials: a brochure for ESRD patients that includes a postcard they can send to family members, posters for dialysis clinics and buttons for clinic staff, and a video. The materials were promoted to dialysis centers in the four NKDEP pilot site communities (Atlanta, Baltimore, Cleveland and Jackson, MS). Sample materials were sent to 135 centers, and 33 percent responded with an order. Materials are also available to order from the NKDEP website.
- Karen Toll gave an overview of a materials audit that NKDEP conducted in February 2005 to determine how dialysis centers used existing materials and what additional materials might be useful.
 - Method: Conducted telephone interviews with 21 people (10 responders from pilot sites, 5 non-responders and 6 new centers).

- Feedback on existing NKDEP materials: Overall, very positive. Clinic staff liked the materials, especially the brochure; felt that African-American focus was appropriate; noted that materials filled a gap; video wasn't used as frequently (facility resources were an obstacle) but those who did use it had high enthusiasm for it.
- Other findings: Staff use free info, though some corporate chains were limited to using materials produced by the national office; most people gave materials to new patients on arrival (though some noted that new patients might not be as receptive given all going on with them); shared ideas for new materials and suggested other venues.
- Conclusions: Existing materials are sufficient; challenge is greater promotion. One idea: repackage current materials, with a few additional pieces, as a Family Education Kit that could be sent to a larger group of dialysis clinics.
- Current promotion efforts: mailings to large dialysis organizations, presentations at key conferences, and via NKDEP website.

General Discussion

- Mark led the group in a general discussion about engaging ESRD patients as ambassadors to reach out to their family members, and the best channels for reaching them. He asked the team to consider several questions:
 - Are people with ESRD motivated to teach others?
 - Is the dialysis center the way to reach patients?
 - What are barriers to getting the materials used?
 - What are the most teachable moments / best ways to engage ESRD patients?
- The group debated whether patients would be ready to hear this information at the dialysis center, and if they would be willing to speak to their families or larger groups. Members mentioned that there are usually a handful of motivated patients who might be interested, and that patients do listen to other patients. Those who have been on dialysis longer might be more willing to speak to others.
- Several members expressed concern about patients educating others and the accuracy of the information conveyed. Members mentioned the importance of training patients on how to talk to family members.
- Several people mentioned that the best approach to patient education is repetition and finding every opportunity to present information to patients.
- The group discussed the importance of the venue for engaging patients, and suggested outreach through churches, PCPs, and NKF's KEEP screenings.
- There was discussion about whether the ESRD patient should focus education to family members only on kidney failure as risk factor to keep it simple, or does it make sense to also ask them to speak to family members about other risk factors.

- The group strongly agreed that dialysis centers are a good opportunity to disseminate information, even though there currently are organizational barriers to making it happen regularly. They thought NKDEP should try to reach ESRD patients through dialysis centers. However, since it often takes a while before patients are ready for more information and support, members thought initiation of dialysis was not the best time to approach patients.
- The group discussed how family education was not part of the current intake process, and how some facilities have education groups for people to better understand CKD.

Materials and Partners

- The group discussed several questions/issues:
 - Do we want to use the existing materials?
 - Who are the right partners?
 - National Kidney Month in March
 - Marketing and dissemination
- Elisa recapped marketing efforts to date, including presentations at various conferences, inclusion on the website, and the mailing to the pilot sites.
- Elisa acknowledged that there has not yet been an official roll-out of dialysis program – NKDEP hasn't aggressively marketed materials or met with key people (e.g., medical officers) at large dialysis organizations (LDOs), which could be an initial aim of this working group. DWG members could help promote the NKDEP dialysis initiative within their organizations.
- She noted that effective strategies should drive materials – not vice versa. While it would be great to distribute our current inventory, we shouldn't consider that the objective.
- The primary comment on existing materials included: poster too small for facilities, could work in a nephrologist exam room, but will get lost in the visual clutter of a dialysis facility.
- Ideas for use of existing materials included:
 - Family Education Kit to repackage current materials.
 - Having facilities encourage use of the postcard by each patient, which then includes information about a local KEEP screening. Return of the cards to the screening could be a mechanism to track effectiveness of the postcard in motivating people to get tested.
- Several ideas for new materials/approaches were proposed by the group, including:
 - Calendar for the dialysis units.
 - Display in dialysis center lobby targeting patients or family members directly.
 - Develop two buttons: one that raises awareness about family member risk and getting tested, the other that specifies the tests that should be done.

- Materials adapted into Spanish.
- Use of lay health advisor, or informal community leaders who educate their peer group about CKD.
- Suggestions for marketing the materials included:
 - Letter to LDOs and independent facilities asking them to help us raise awareness among their facilities and staff that these materials are developed.
 - Work with the renal networks by distributing at annual renal network meetings, informing Patient Services Committees, and attending professional education events.
 - Get on agenda or have a booth at national meetings, such as Congressional Black Caucus, National Urban League, NAACP.
 - Inclusion of materials in CMS new patient packet.
 - Work with nephrologists.
 - Work with Baptist Conventions (there are three) and Black Muslims (e.g., Abundant Life Clinic).
 - Getting a national pharmacy franchise involved – some of the larger chains have in-store clinics and nurse practitioners who could distribute our materials.
 - Inviting a broader range of people to join the Working Group.
 - Integrate the materials into American Diabetes Association’s Project Power program.
 - Address CKD as part of holistic approach to issues affecting minority communities.
 - Short-term marketing around National Kidney Month in March.
- Ideas for publications or other organizational channels where materials could be promoted were:
 - Nephrology News & Issues
 - Family Focus
 - Dialysis and Transplantation
 - Nephrology Nursing Journal
 - NKF Three Professional Councils: CNS and CNW list serves, websites, cybernephrology chairs
 - ANNA website
 - AAKP website
 - Renal Web
 - Forum of ESRD Network and each individual network websites
 - National Library of Medicine – tutorial
 - State chapters of places like NANT and ANNA, ETC.
 - Free clinics

- Public health departments
- Community health centers
- The group agreed that NKDEP should focus in the short term on marketing existing materials, not creating new materials.
- Another suggestion was to conduct formative research with the families of dialysis patients, and also develop a logic model, organizing objectives, activities, and evaluation measures.

Closing Discussion

- Mark summarized the consensus: the first step is to reenergize marketing efforts to promote and disseminate the existing materials. The next steps are to share more information with DWG and schedule a follow-up conference call. Partnerships can expand beyond the renal networks. Evaluation tools should also be developed.
- Mark also asked people to identify contacts they have or organizations to which they'd be willing to reach out. Elisa offered to provide additional information from NKDEP to help them with their outreach efforts.

Action Items

- Elisa offered to put together a list of who NKDEP is currently working with and have the Working Group tell us who is missing.
- Peter Hayden offered to put NKDEP in touch with his contacts at the Baptist Conventions and with Black Muslim groups.
- Dave Fracalossy is on editorial board of Nephrology News and Issues, and offered to help place an article.
- Wendy asked to bring the NKDEP tabletop display to a meeting in March.
- Sandra Quinn can reach out to Sheridan Broadcasting, which develops health messages for their network of AM stations. She also has strong partnerships from the Healthy Black Families program in Pittsburgh.