



RENAL OUTREACH

ESRD Networks 9/10

Special Family Edition

Winter 2002/Vol XIII, No. 1

ESRD: A Family Affair

Family Questionnaire

(Introduction by Jan Nordsiek)

As the spouse of a 17-year dialysis patient, I have long been frustrated by the lack of information and support available for the family members of dialysis patients.

There is so much for our loved ones but so little for us. We balance little league, homework, good days and bad days, medical emergencies, birthday parties, a job and the BILLS. We are the silent partners but we sit on the outside looking in and still must keep everything going as "normal."

Last year, I decided to take a more active role in finding solutions by joining the Family subcommittee of The Renal Network's Patient Leadership Committee. Our subcommittee is made up of spouses, patients and renal staff. We are looking at a variety of means to reach out and offer assistance to those who live with the dialysis patient.

Our current project is a proposed video that will identify major areas of family stress.

We hope it will serve as a means of building awareness for the families of newly diagnosed patients.

We have discussed organizing a one-day seminar for the families of current patients as well as creating a variety of informational materials.

Family Stress – A journey to understanding.

As patients, family and staff coping with end-stage renal disease, we know that dealing with kidney failure is a family affair. As the patient's life is turned upside down, so are the lives of their family members.

Understanding the effects of end-stage renal disease on the family is not simple. Kidney failure hits the young family with small children; the retired couple with multiplecare needs; and, the single person that must depend on an extended family. There are many more scenarios --- but you get the idea.

Continued on page 3

The Patient Services

Department,

working together with the Patient Leadership Committee (PLC) and the internship program at Purdue University/ Indianapolis, has created an internet resource for patients and their families and friends. This is a work-in-progress and there is much, much more to come.

This is your web site.

If you would like to contribute an article, some favorite kidney facts or recipes... just contact us or just send your ideas, comments and contributions to the Patient Services Department in care of the Network office.

Introducing

www.kidneypatientnews.org

A new website especially designed for renal patients and family members

Patients

Find articles written by patients for patients and more...

Family

Discover what others have to say about how they learned to cope.

Resources

Download Renal Network resources.

Links

Connect to other web sites.

Understanding the effects...

Figuring out the needs of families of end-stage renal disease patients, and how to best address them, has become the first order of business. We wanted to go beyond the immediate experience of our members to learn how to address these important questions.

We developed a survey to look into the stress faced by family members. We went to our own units and asked the families to respond. The results from this first effort provided more insight but the replies received were still too few in number. We wanted to include all segments of the dialysis family.

Therefore, we decided to list the questions in an issue of the ***Renal Outreach***.

Your responses...

What a fantastic experience to have received all of your responses to our Family Members Questionnaire. We collected 374 completed documents from the family members, caregivers and friends of dialysis patients in our network area.

Your responses to the questionnaire are helping the Family subcommittee of the Patient Leadership Committee (PLC) to identify those areas of stress, which affect the families of a dialysis patient most.

While Network staff prepared a summary of your responses, the subcommittee reviewed your personal comments made on the questionnaires. How easy it is to identify with personal insights they provide.

Many of you wrote additional notes ranging from problems associated with bathing with a permacath, lost travel opportunities, dealing with depression, itching, non-compliance and special diets, costly drug prescriptions, and personality changes.

Just the kind of issues family members of dialysis patients face every day.

Though it frequently feels as if these issues are ours alone to handle, in reality there are many, many others feeling the same way. Your responses and comments on the questionnaire are helping us find ways to help you.

It is taking some time to pull all this together but the subcommittee is working hard to make it happen. If you have suggestions, comments or thoughts that you didn't previously include, please let us know by writing to us at The Renal Network office.

Who are the respondents?

Respondents...

...to our questionnaire (see figure 1) were overwhelmingly women who account for 64% of all returns.

They responded in an almost 2:1 ratio. This outcome is not surprising, as women are more likely to identify with “family or caregiving” roles and also, may be more willing to share their story. Two percent of the returns did not check a gender.

Respondent Gender - Figure 1

Men	34%
Women	64%
Unknown	2%

The actual patient population Network-wide is more evenly distributed with 53% of hemodialysis patients being male and 47% being female. We can assume that caregivers for women patients are underrepresented among our respondents.

The numbers for peritoneal patients are even closer with 51% males and 49% females (2000 Annual Statistical Report for End-Stage Renal Disease Network 9/10).

Respondents tended to be older with close to half being over the age of 60 (see figure 2).

Age in years - Figure 2

	Respondents	Patients
Under 18	0	0
18 – 25	>1%	2%
26 – 35	7%	3%
36 – 45	10%	11%
46 – 60	27%	19%
Over 60	49%	60%
Unknown	6%	5%

Another 27% were between the ages of 46 – 60 while only 18% of those returning the questionnaire were between the ages of 18 – 45.

Patient ages (figure 2), as described by respondents, also tended to fall in the over 60 category (with 60% being reported in that age group), while 19% fell in the 46 – 60 age group. Only 16% of patients were reported as being less than 45 years of age.

At first it would seem that older patients are over represented among respondents. Yet according to the 2000 Annual Statistical Report, hemodialysis patients range in age from:

- 16% in the 18 – 44 bracket
- 36% in the 45 – 64 group
- 48% in the over 65 yrs of age group

... while, the peritoneal patient group is somewhat younger with:

Continued on page 5

- 2% under 18 years of age,
- 24% in the 18 – 44 age group,
- 43% in the 45 – 63 category and
- 31% in the over 65 set.

In general, it can be said that the questionnaire adequately reflects the Network patient population except for the under 18 years of age group which is not represented at all.

In addition, all four of the states in our Network area were represented in numbers closely approximating the distribution of patients.

The relationship of the respondents to the patients is outlined in figure 3. Spouses are the primary caregivers identified through this inquiry.

Relationship to Patient - Figure 3

Spouse	72%
Parent	8%
Child	9%
Other	5%
Unknown	6%

Figure 4 represents the number of years patients and their families have been coping with life on dialysis. Close to 30% have been managing dialysis for over three years. Another 50% have been dealing with dialysis from 1 to 3 years.

Only 18% are in their first year of dialysis, which is considered to be a period of adjustment.

Years on dialysis - Figure 4

Under 1	18%
1 – 3	50%
Over 3	29%
Unknown	3%

Living with dialysis

Yet how long does adjustment to living with dialysis really take? And what is “living with dialysis” from the family member’s point of view?

One family member remarks, “...as my husband’s caregiver, I have been told basically to, ‘deal with it.’ Well just how do you deal with it? No one ever seems to have answers.”

Many family members feel alone and unsupported: “My spouse {*a patient for six years*} does not contribute to the daily needs of the children and the household. All of the responsibility is left to me, the healthy spouse and that is very stressful.”

Or, “My husband relies on me more and more as time goes on. I try hard to encourage him to be more independent and to make more decisions and to get him more involved in his care.”

Many patients seem to rely solely on family members even when others might be in a position to help: “Patients need other support systems besides family members to talk to... like the social

Continued on page 6

worker or clergy... but *{patients}* find it hard to confide in someone else.”

Some family members are able to cope with the day-to-day needs but have trouble adjusting emotionally: “Seeing mom suffer is the biggest problem.” Or they are coping with the emotional fallout of the patient’s reaction: “...*{Patient’s}* personality has changed...he’s angry, frustrated, and can’t accept the loss of control over his life.”

And, many are coping with fear--- their own and that of the patient: “...we worry about how long his body will hold up,” or “...mom is very demanding, insecure... and panics... so we have lots of emergency room visits.”

And even for families that are coping well, something could change at any moment to upset the balance that has been established: “If I should become unable to drive--- it would be very stressful on both of us.” Such feelings of fear and worry can create a daily current of anxiety and unease.

The stresses identified...

most frequently by respondents were tiredness (86%), depression (76%), and diet and sleep (both selected by 73%). See figure 5 (Total % Selecting column) for a complete listing. Although selected most frequently, none of the above were seen as major stressors. For example, of the 86% who selected tiredness as a stress factor, only 25% identified it as a major stress in their lives.

Looking only at the *Major Stress* column, you can see that 40% of the total respondents selected work and 38% chose medical expenses as having a major impact on their lives. Then compare these outcomes with those found under the *Minimal Stress* column. For example, a full 50% of the respondents that said diet was a stress in their family noted that it was a minor but consistent sore point in their daily lives.

Although the numbers on their own can tell a story, it’s the voices behind those figures that describes what is happening in the individual family.

For example on tiredness one person writes, “*{patient}* sleeps much of the time. It’s not much of a life for either one of us.” On depression: “*{patient}* is morbidly depressed and his outlook is all doom and gloom...refuses to take medication...say’s he’s not depressed!” And: “...depression due to long term caregiving of a loved one...due to feelings of helplessness and... hopelessness.” On diet: “My husband has lost his appetite...it’s a struggle with every meal.” On sleep: “He can’t sleep at night ...sleeps an average of two hours.”

Work is a major issue for caregivers: “...*{staying employed}* and still being able to take care of my wife. We are about to lose our house.” Or, “taking early retirement at age 55 to become a caregiver, was a big loss to me.”

Continued on page 7

The stresses identified ...

Instead of our dreams, we have this daily fight with dialysis.”

Many other respondents spoke of the financial burden of prescription drugs, the time that dialysis takes out of their day and the stress of dealing with the facility, Medicare and other insurance carriers. Some respondents asked for support groups, better information about kidney failure, how dialysis works and the effects of dialysis on the patient.

Although the responses received were not new to the group members, the impact of reading them all together was nonetheless overwhelming. As one member of our subcommittee put it: “the

{respondents} comments sound like a collective cry for help.” Many of the issues brought up are ones that as a committee, we can do nothing about. But we will work to address those that we can. You can help by offering your ideas, by joining us on this committee or by simply offering support to other family members in your facility.

Our next issue of the *Renal Outreach* will feature an article on one of the many concerns raised by the survey. For now we have listed some useful information on the back cover for your immediate use.

Committee members: Bob Nordsiek, (Chairperson), Celia Chretien, Jan Nordsiek, and Pearl Hirsh

Figure 5 - Percent total of all respondents selecting each stress and percent breakdown of each issue according to identification as major, moderate or minimal stress (last three columns may not add up to 100%)

Issues	Total % Selecting	Major Stress	Moderate Stress	Minimal Stress
Diet	73	11	37	50
Work	38	40	40	20
Depression	76	25	33	42
Income	41	34	40	26
Medical Expenses	69	38	31	30
Sleep	73	29	32	39
Transportation	56	29	26	44
Tiredness	86	25	38	36
Itchy skin	64	17	34	47
Sexual Dysfunction	50	22	33	43
Access	66	21	38	41

Resources for families...

Books

Kievman, Beverly & Blackmun, Susie. (1989). *For Better or Worse, A couples' guide to dealing with chronic illness*. Chicago: Contemporary Books.

McGonigle, Chris. (1999). *Surviving Your Spouse's Chronic Illness*. New York: Holt.

Rolland, John S. (1994). *Families, Illness, and Disability*. New York: Basic Books.

Welsh, Linda & Betancourt, Marian. (1996). *Chronic illness and the Family*: Massachusetts: Adams Media Corporation.

Booklets

New Life, New Hope: A Book for Families & Friends of Renal Patients (1997). Life Options Rehabilitation Program (call 1-800-468-7777 for free copy)

Newsletter

Family Focus Newspaper, published by The National Kidney Foundation (to subscribe call 800-622-9010 or visit their web site: www.nkf.org).

Article

Heisick, Mary. "Self-Care: The Importance of Socialization for Caregivers." November, 2001 (Vol.17, No.3). *aakpRENALIFE*.

Web sites

www.ikidney.com

www.care-givers.com

www.kidneypatientnews.org

www.inforenal.com (Stay in Touch Program or call 1-877-543-6394)

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This newsletter is published under CMS Contracts 500-00-NW09 & 500-00-NW10