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## Pain, control over treatment, and compliance in dialysis and transplant patients

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**Pain, control over treatment, and compliance in dialysis and transplant patients.** Pain was surveyed via structured interview and the McGill Pain Questionnaire in 53 dialysis and 27 transplant patients. Increased patient control over the dialysis procedure was not associated with a reduction in pain though perceived control may have been. Compliance with the dialysis regimen did not predict pain and the validity of the category "dialysis headache" was questioned. Overall, transplant recipients did not report significantly less pain than dialysis patients. Self-reported depression was correlated positively with pain. The clinical implications of these findings are discussed.

**Les douleurs, le contrôle thérapeutique et l'adaptation chez des malades dialysés et transplantés.** Une étude de la douleur a été entreprise chez 53 dialysés et 27 transplantés au cours d'entretiens, et à l'aide d'un questionnaire (McGill Pain Questionnaire). Une plus grande participation du malade à la dialyse n'allait pas de pair avec une réduction des douleurs, alors que le contrôle perçu peut avoir eu cet effect. Une bonne adaptation à la dialyse ne permettait pas de prédire les douleurs, et la validité de la classification "céphalées au cours de dialyses" a été remise en question. D'une façon générale, les transplantés n'indiquaient pas des douleurs significativement inférieures à celles des dialysés. L'état dépressif rapporté par les malades était positivement corrélé avec les douleurs. Les implications cliniques de ces résultats sont discutées.

From the patient's point of view, pain control is one of the critical aspects of medical care. Recent research with diverse populations has shown that pain may be one of the basic dimensions of the quality of life of medical patients [1]. Despite this, there is very little systematic information concerning pain in end-stage renal disease (ESRD) patients. While clinical impressions strongly suggest that technical advances have greatly reduced the incidence and severity of pain problems for dialysis patients, there is little empirical evidence to support this view. Recent research concerning dialysis pain has focused on limited populations with one specific type of pain [2–4] or has included pain as one of a number of dialysis-related complications [5]. To the authors' knowledge, controlled re-

search concerning pain after successful transplantation does not exist.

Moreover, the existing research has not considered possible psychosocial influences on pain [6–9]. Among those that seem particularly relevant to an ESRD population are expectations about or information concerning pain [10], staff and other patient reactions to pain [11]; mood states such as anxiety or depression [8] and the extent of control over the dialysis procedure [12, 13]. The effects of increased control over treatment on pain are particularly relevant because proponents of self-care dialysis have stressed its salutary effects [14, 15]. This claim is supported by a large body of psychological research [9, 12] and theorizing, but it has never been tested in a dialysis population. Psychosocial research has also been concerned with the measurement of pain. Traditionally used measures of incidence or frequency are useful preliminary indices; however, they ignore what may be the most critical aspect of pain to the patient—intensity. Recently developed methods take this into account and have been validated with numerous medical populations [16, 17]; however, these have not been used with an ESRD population.

The following study has several purposes: (1) Using recently developed methods, it attempts to provide a descriptive survey of pain in hemodialysis and transplant patients; (2) it examines whether or not self-care hemodialysis results in a reduction of pain; (3) it investigates the relationship between compliance with the dialysis regimen and pain; (4) it examines the validity of the category of "dialysis headache"; (5) it compares the prevalence and severity of pain in dialysis and transplant populations.

### Methods

**Dialysis patients.** Fifty-three dialysis patients including 15 home care, 19 hospital self-care, and 19 hospital staff care patients were interviewed. Patients were selected in the following manner: All home care patients in the Montreal area during the period June 1979 to March 1980 ( $N = 16$ ) were telephoned and asked to participate; 15 patients agreed. During the same period, all hospital staff care patients at the Royal Victoria Hospital (RVH) and Centre Hospitalier Côte des Neiges (CHCN) who spoke either French, English, or Greek ( $N = 21$ )

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Table 1. Background characteristics of sample

	Staff-hospital	Self-hospital	Home	Transplant
Physical status <sup>a, c</sup>	3.5	4.1	4.2	4.4
Age	49.2	45.5	41.2	40.4
Years on dialysis <sup>e</sup>	2.8	2.2	2.8	1.4
IQ <sup>b</sup>	108 (21.2)	112 (21.3)	122 (25.1)	110 (22.3)
Number of previous transplants <sup>e</sup>	0.52	0.16	0.2	0.07
Probability of receiving a transplant <sup>c, f</sup>	1.7	2.8	1.5	—
Sex <sup>e</sup>	7M; 12F	12M; 7F	13M; 2F	17M; 10F
Marital status:				
Married	12	13	10	16
Not married	7	6	5	11
Employment status:				
Unemployed	1	1	3	6
Employed	10	14	10	15
Other (for example, student, housewife, retired)	8	4	2	6
Educational level <sup>d, e</sup>	4.0	3.5	4.5	5.0

<sup>a</sup> Rated by staff on a 5-point scale ranging from very poor (1) to very good (5).

<sup>b</sup> IQ was estimated from two subtests of the WAIS, information and picture completion. The sum of these two subtests is very highly correlated with total IQ,  $r = 0.9$  [18]. Scores in parentheses are raw scores for these two subtests transformed into full scale IQ.

<sup>c</sup> Rated by staff on a 5-point scale from very likely to very unlikely.

<sup>d</sup> Coded on a 0 to 8 scale: 0, none; 1, some elementary; 2, completed elementary; 3, some high school; 4, completed high school; 5, some college; 6, completed college; 7, some graduate or professional school; 8, completed graduate or professional school.

<sup>e</sup>  $P < 0.05$

<sup>f</sup>  $P < 0.01$

were approached with the exception of two elderly patients in very poor physical condition. Two patients declined to participate. Finally, hospital self-care patients at the CHCN and Notre Dame Hospital were approached unsystematically until 19 interviews had been completed. There was a total of 37 hospital self-care patients at these hospitals at that time.

**Transplant patients.** Twenty-seven post-transplant patients who visited the hospital for their annual checkup or for a clinic appointment during the period April 20 to July 15, 1980, and who had had a successfully functioning graft for at least 6 months were asked to participate; all agreed. All of these patients had been transplanted at the RVH.

Table 1 presents the relevant background and demographic data for the dialysis and transplant patients. The four groups significantly differ on physical status ( $F_{3,76} = 3.6$ ,  $P = 0.01$  staff < trans), number of years on dialysis ( $F_{3,75} = 9.1$ ,  $P < 0.05$  trans < staff and home), IQ ( $F_{3,62} = 3.01$ ,  $P < 0.05$ , home > trans), number of previous transplants ( $F_{3,74} = 2.9$ ,  $P < 0.05$ , trans < staff), probability of receiving a transplant ( $F_{2,50} = 5.6$ ,  $P < 0.01$ , self > staff and home), sex ratio ( $\chi^2 = 8.9$ , 3df,  $P < 0.05$ ) and educational level ( $F_{3,76} = 3.89$ ,  $P = 0.01$ , trans > self-hospital). These differences result from limited local availability of certain treatment modalities (for example, home dialysis) and from various selection procedures and biases exercised by hospital staff.

**Materials.** A structured pain interview including questions from the McGill [16] and North Carolina [19] Pain Question-

naires was utilized. The interview included specific questions concerning the nature, duration, quality, significance, frequency, location, history of, reactions to, methods of dealing with, and explanations for experienced pain.<sup>1</sup>

The McGill Pain Questionnaire (MPQ) [16] developed by Melzack and his associates formed an important part of the structured interview. The central feature of this instrument is a series of words that patients select to describe their subjective pain experience. These words are divided into three classes which correspond to the sensory, affective, and evaluative aspects of pain and have been rank-ordered according to pain intensity. Scoring of the MPQ depends on the number and rank order of the words chosen and can be treated statistically. The instrument has been validated with numerous types of pain and is sensitive to changes in the intensity of pain resulting from treatment [16].

**Procedure.** All the structured interviews were done by an experienced interviewer (DK). For dialysis patients information was gathered for every type of current pain reported on or off dialysis. Similar questions were asked of transplant patients concerning their current pain; they also were asked briefly about pain they had experienced while on dialysis. Dialysis

<sup>1</sup>A copy of the interview may be obtained by writing to Y. M. Binik, Department of Psychology, McGill University, 1205 Dr. Penfield Ave., Montreal, PQ H3A 1B1, Canada.

Table 2. Pain on dialysis

	Cramps	Headaches	Abdominal	Fistula	Chest	Bone	Itchiness	Other
Percentage of patients reporting pain	81.1	62.3	17	15.1	13.2	11.3	9.4	9.4
Percentage considering it a significant problem	16	18	33	25	57	50	40	20
Dialysis onset of pain, %								
Prior	—	9	—	12	—	16.6	—	—
Start	2	28	11	50	14.2	16.1	40	—
1 hr	—	13	11	12.5	—	—	—	—
Mid	22	25	33	—	28.6	—	—	—
End	74	19	22	—	28.6	16.6	20	—
No pattern	1	6	22	25	28.6	50	40	—
Average duration, min	13	102	45	111	81	246	118	—
Location, %	Foot-lower leg (55) Calf (23) Entire leg (12) Hands & feet (9)	Forehead (69) Temples (6) Back of head & neck (3) Entire head (21)	Abdomen-stomach (100)	Arm (86) Fistula (14)	Chest (100)	Lower back (33) Other (50)	All over the skin (100) Several points (17)	Eye (20) Neck (20) Sole (20) Ligaments in several areas (20) Muscle behind knee (20)
Frequency, % dialyses	31	28	34	22	21	48	31	—
$\bar{X}$ McGill Pain Ques. Score	10.7	6.2	7.3	3.8	6.4	11.3	4.4	—
Percentage having pain before kidney failure	9.3	15	11.1	—	28.6	33.3	—	—
Has pain changed since started dialysis, % yes	70	72	89	63	86	83	80	—
How different %	90 More frequent & intense before	86 More frequent & intense before	100 More frequent & intense before	66 More frequent & intense before	— More frequent & intense before	100 No discernible pattern	— No discernible pattern	—
Affects behavior on dialysis, % yes	25	33	22	38	25	33	50	—
Treatment received, %								
Meds.	—	73	22	—	43	33	40	—
Saline	79	—	—	—	—	—	—	—
Other	—	3	11	37	43	17	—	—
None	21	24	67	63	14	33	60	—
What causes pain? %								
Dialysis	16	41	56	22	—	14	20	—
Ultrafil.	79	3	11	44	—	—	—	—
Disequilib.	—	9	—	—	17	—	—	—
Emotional	—	—	—	—	—	14	—	—
Decalcifi.	—	—	—	—	50	—	—	—
Unknown	2	44	22	22	—	57	60	—
Other	2	3	11	11	33	14	20	—
What decreases pain, %								
Meds.	—	69	—	22	58	43	48	—
Saline	72	3	11	22	—	—	—	—
Dialysis	5	6	—	11	—	—	—	—
Nothing	7	22	44	44	33	29	60	—
Other	5	—	22	—	—	—	—	—

Table 3. Pain off dialysis

	Cramps	Headaches	Bone	Itchiness	Chest	Back	Other
Percentage of patients reporting pain	62	43	15	15	13	5.7	22.6
Percentage considering it a significant problem	15	22	50	38	29	33	25
Average duration, <i>min</i>	115	95	302	248	47	173	—
Location, (%)	Foot lower leg (45) Hands & feet (23) Calf (13)  Entire leg (10)  Abdomen (3) Hand (3) Upper leg (3)	Forehead (71) Entire head (16) Temples (8)  Back of head & neck (4)	Lower back (14) Several points (14) Hands & feet (14) Shoulders (14)  Other (43)	All over the skin (100)	Chest (100)	Lower back (33) Shoulders (33)  Upper chest (33)	Abdominal (50) Several points (8) Entire leg (8) Other (33)
$\bar{X}$ McGill Pain Ques. Score	9.9	7	8.4	4.4	6.9	9.3	—
Percentage having pain before kidney failure	12	52	25	—	29	33	—
Has pain changed since started dialysis, % <i>yes</i>	84.5	69.6	75	50	57	33	—
How different, (%)	(100) More frequent & intense then	(100) More frequent & intense then	(66) More frequent & intense now	(100) More frequent & intense now	(100) More frequent & intense then	(100) More frequent & intense now	—
Treatment received, %							
Meds.	3	74	50	25	57	33	—
Hypnosis	—	—	12	13	—	—	—
Other	21	—	—	13	14	33	—
Nothing	76	26	38	50	29	33	—
What causes pain? %							
Dialysis	27	44	—	78	29	—	—
Ultrafil.	18	4	—	—	—	—	—
Disequilib.	6	17	13	—	—	—	—
Emotional	—	—	—	—	14	—	—
Unknown	46	30	—	78	29	—	—
Other	3	4	24	11	14	66	—
What decreases pain, %							
Meds.	3	65	25	22	43	33	—
Dialysis	—	9	—	—	—	—	—
Rest	3	13	25	—	29	33	—
Other	—	—	12	22	—	—	—
Nothing	3	13	37	56	29	—	—

patient interviews occurred during hemodialysis sessions either in the hospital or at home, while post-transplant patients were interviewed during their annual hospital admission checkups or before or after clinic appointments. The average length of interviews was about 45 min but varied greatly depending on the amount of experienced pain. All patients were aware that the interviews were strictly confidential and that group data only would be reported to the staff.

After completion of the interviews, five raters (two nephrologists and three psychologists) were given capsule descriptions of typical headaches reported by dialysis patients both on and off dialysis. Each description included the following categories of information: (1) occurrence prior to onset of kidney failure; (2) occurrence prior to starting dialysis; (3) location; (4) onset during dialysis session; (5) duration; (6) percentage of dialysis sessions on which headache occurs; (7) onset symptoms of

Table 4. Pain reported by post-transplant patients

	Headaches	Kidney pain	Bone-joint	Cramps	Back	Chest	Other
Percentage of patients reporting pain	59	33	30	19	15	4	41
Percentage considering it a significant problem	19	—	63	20	25	100	9
Average duration, min	246	12	482	168	640	800	—
Location, (%)	Forehead (63) Back of head & neck (31) Entire head (6)	New kidney (100)	Knee (38) Knee & other joints (38) Shoulder (25)	Hands (40) Feet (40) Stomach (20)	Small of back (60) Lower back (40)	Left side of chest (100)	Eye Pain (18) Menstrual cramps (9) Urinary tract (9) Finger (18) Leg (bypass) (9) Back of neck (9) Left underside of foot (9) Fistula (18)
Frequency of pain episodes/month	2.8	.7	3.9	1.9	1.8	3.0	—
$\bar{X}$ McGill Pain Ques. Score	10.4	3.1	4.0	14.6	7.0	1.0	—
Percentage having pain before kidney failure	56	—	—	—	50	—	—
Treatments received, %							
Drugs	37	—	12	—	—	100	—
None	63	100	88	100	100	—	—
What causes pain, %							
Don't know	44	67	75	100	25	100	—
Tension, fatigue	25	33	25	—	—	—	—
Other	—	—	—	—	75	—	—
What decreases pain, %							
Drugs	50	—	12	—	—	—	—
Rest	25	56	25	—	50	—	—
Nothing	—	44	50	—	50	100	—
Salt-massage-heat	—	—	—	75	—	—	—
Other	25	—	13	25	—	—	—

headache; (8) medications taken; (9) factors which increase headache pain; (10) adjectives from MPQ to describe pain; (11) typical associated symptoms; (12) intensity rating on 1 (mild) to 5 (excruciating) scale. The raters were then asked to classify each headache into one of five diagnostic categories (migraine, muscle, contraction, mixed muscle contraction-migraine, renal failure, and dialysis headaches) according to a set of explicit criteria. For the first three categories these criteria were derived from the headache literature [20–22]. The criteria for classification as a renal failure headache included onset associated with renal disease, bilateral position, throbbing quality, and associated hypertension. Dialysis headaches were those which were associated strictly with the dialysis procedure, were completely new symptoms in the patient's medical history, and which started as a mild bifrontal ache and often built up into a more severe throbbing headache usually worse in the reclining position [23, 24].

In addition a variety of compliance measures were gathered from each patient file. These included blood urea nitrogen (BUN), inorganic phosphates, and potassium measures for the 6 months prior to the interview and weight gain data between each of the last 21 dialyses.

### Results

*Pain on dialysis.* Cramps (81%) and headaches (62%) were the most commonly reported types of pain on dialysis. In addition, abdominal (17%), fistula (15%), chest (13%), and bone (11%) pain were reported. Nine percent of the hemodialysis patients reported persistent itchiness and considered it painful. A variety of other types of pain located in the eye, knee, neck, and sole of the foot also were reported; however, these results were relatively infrequent and idiosyncratic. Other side effects of the dialysis procedure such as nausea and dizziness were not considered painful by patients and are not further discussed

**Table 5.** Dialysis pain reported by post-transplant patients

Type/area of pain	Percentage of patients reporting pain
Cramps	51.9
Headaches	66.7
Fistula	7.4
Abdominal	37
Bone	3.7
Chest	3.7
Itching	3.7
Other	7.4

here. Although headaches and cramps were reported most frequently, they were considered significant problems by less than 20% of the patients experiencing them. The other types of pain were reported much less frequently, but considered more serious when they occurred. Most patients reporting pain indicated that the pain was different at the time of the interview than it had been when they initiated dialysis. Except for bone pain and itchiness the occurrence was less frequent and the intensity lower with increased time since the initiation of dialysis. In addition, many patients reported similar types of pain prior to the onset of kidney failure. Table 2 summarizes these data and includes additional information concerning the duration, onset, treatments for, factors which cause or decrease pain, and so forth.

**Pain off dialysis.** Table 3 presents similar data for the types of pain experienced by the same patients off dialysis. Pain reported off dialysis is strikingly similar to pain reported on dialysis with several minor exceptions including the absence of fistula pain, the inclusion of back pain, an increased duration of cramps and a worsening of bone pain with time.

**Pain after transplantation.** For headaches, chest and back pain post-transplant patient reports were very similar to those of dialysis patients. There were, however, differences in other categories. The incidence of cramps was reduced greatly although the percentage of patients considering it a significant problem was similar. Bone pain in these patients seemed better characterized as bone-joint pain and was most often noted in the knee area. A new type of pain located in the transplanted kidney was reported by one third of the patients; however, none of them considered it a significant problem. Although the frequency of occurrence of pain was not high, the mean duration of each pain episode for all types of pain was higher than that reported by dialysis patients. Finally, a relatively large number of miscellaneous types of pain were included in the other categories. Table 4 summarizes these data. When asked to recall pain they experienced while on dialysis, post-transplant patients report similar frequencies to those reported by dialysis patients. Table 5 summarizes these data.

**Background variables and pain.** Because our previous analysis of background variables indicated that patients were not assigned to treatments randomly, it was first necessary to investigate which background variables were related significantly to pain before examining the relationship of treatment modality to pain. Table 6 presents the relationship between background variables and the occurrence of cramps and headaches for dialysis patients alone and for dialysis and transplant

patients combined<sup>2</sup>. The most consistent variable predicting the occurrence of headaches and cramps is sex with women reporting significantly more pain than men in four of the six possible cases.

Table 7 presents similar correlations between background variables and pain intensity as measured by the MPQ. A single pain intensity score was generated for each patient by adding individual MPQ scores for each type of pain reported. If the patient did not report a particular pain, a score of 0 was assigned. For pain on dialysis, physical status, ( $r = -0.23, P < 0.05$ ) employment status, ( $r = -0.23, P < 0.05$ ) sex, ( $r = +0.34, P < 0.01$ ) education, ( $r = +0.28, P < 0.01$ ), and marital status ( $r = +0.27, P < 0.05$ ) were correlated significantly with pain on dialysis, that is, patients who were unemployed, in poor health, women, more highly educated, or unmarried reported more pain. For pain off dialysis only physical status was related significantly; however, the same pattern of correlations was evident for employment status, sex, and education and these correlations approached significance. Finally for dialysis and transplant patients combined, only physical ( $r = -0.22, P < 0.05$ ) and employment status ( $r = -0.21, P < 0.05$ ) were correlated significantly with total pain, that is, patients in poor health or who were unemployed tended to experience more pain. Background variables significantly correlated with pain dependent variables at the  $P < 0.05$  level were adopted as covariates in subsequent analyses.

**Control over dialysis, depression, and pain.** Two different types of dependent variables were used to examine whether the different forms of dialysis or transplantation were associated differentially with pain. The first type used frequency data concerning either the occurrence or absence of pain. Simple or multiway contingency tables stratified for significant background variables were constructed to analyze these data. None of the simple or multiway analyses demonstrated a significant association between treatment mode and the occurrence of headaches or cramps.

The second type of analysis used the McGill Pain Questionnaire score as the major dependent variable. The use of this dependent measure allowed us to analyze across different pains by deriving a total pain score for each patient by adding individual pain scores for each type of pain. A series of hierarchical multiple regression analyses [25] using the MPQ scores were performed entering significant background variables at the first step and a set of dummy coded variables to represent different treatment modes (for example, staff, self, home dialysis and transplantation) at step two. By using this type of analysis, we statistically controlled for significant background variables relating to pain and then investigated the relationship of treatment mode to the dependent variables (that is, pain). None of these analyses indicated a significant statistical association between treatment mode and pain on dialysis, pain on dialysis weighted by frequency of occurrence, pain off dialysis, or a weighted average of total pain on and off dialysis.

Thirty-one of the dialysis patients who participated in this study concurrently participated in another of our studies which

<sup>2</sup>Only the data for headaches and cramps were evaluated in this fashion because the other types of pain were too infrequent for statistical evaluation.

**Table 6.** Relationship of background variables to the occurrence of headaches and cramps for dialysis patients ( $N = 53$ ) and for dialysis and transplant patients combined ( $N = 80$ )<sup>a</sup>

	Dialysis patients alone ( $N = 53$ )				Dialysis and transplant combined ( $N = 80$ )	
	Headaches on dialysis	Headaches off dialysis	Cramps on dialysis	Cramps off dialysis	Headaches	Cramps
Physical status	-0.1	-0.33 <sup>c</sup>	-0.06	-0.1	-0.24 <sup>b</sup>	-0.13
Employment status	$\chi^2 = 0.739$	$\chi^2 = 0.01$	$\chi^2 = 0.04$	$\chi^2 = 0.95$	$\chi^2 = 0.25$	$\chi^2 = 4.0^b$
Sex	$\chi^2 = 5.2^b$	$\chi^2 = 5.95^b$	$\chi^2 = 1.2$	$\chi^2 = 4.5^b$	$\chi^2 = 3.9^b$	$\chi^2 = 1.15$
Education	+0.19	+0.26 <sup>b</sup>	-0.09	-0.04	+0.15	-0.13
Age	-0.12	-0.03	+0.17	-0.02	-0.04	-0.05
IQ	+0.05	+0.16	-0.01	+0.03	+0.09	+0.06
No. of previous transplants	+0.08	+0.06	-0.12	+0.05	+0.11	-0.03
Probability of transplant	+0.02	-0.22 <sup>b</sup>	+0.12	+0.05	+0.02	-0.24 <sup>b</sup>
Marital status	$\chi^2 = 8.2^c$	$\chi^2 = 0.37$	$\chi^2 = 0.53$	$\chi^2 = 0.26$	$\chi^2 = 2.3$	$\chi^2 = 0.43$

<sup>a</sup> Unless otherwise indicated the numbers are Pearson correlation coefficients.

<sup>b</sup>  $P < 0.05$ .

<sup>c</sup>  $P < 0.01$ .

**Table 7.** Pearson correlations of background variables with McGill Pain Questionnaire scores

	Dialysis patients only ( $N = 53$ )		Dialysis and transplant patients combined ( $N = 80$ )
	Pain on dialysis	Pain off dialysis	Total pain
Physical status	-0.25 <sup>a</sup>	-0.27 <sup>a</sup>	-0.22 <sup>a</sup>
Employment status	-0.23 <sup>a</sup>	-0.18	-0.21 <sup>a</sup>
Sex	+0.34 <sup>b</sup>	+0.17	+0.12
Education	+0.28 <sup>b</sup>	+0.17	+0.03
Age	-0.15	-0.06	-0.01
IQ	-0.01	-0.05	-0.01
No. of previous transplants	+0.15	-0.04	-0.06
Probability of a transplant	+0.12	-0.08	-0.06
Marital status	+0.27 <sup>a</sup>	+0.05	+0.07

<sup>a</sup>  $P < 0.05$ .

<sup>b</sup>  $P < 0.01$ .

assessed perceived control over dialysis [26]. Although actual degree of control over dialysis as indicated by treatment mode and perceived control over dialysis as rated by the patient are correlated significantly, they are not identical [26]. Thus, when we examined the correlation between perceived control over dialysis and pain on dialysis as measured by the MPQ, we found a significant negative correlation ( $r = -0.34$ ,  $P < 0.05$ ).

The relationship between pain as measured by the MPQ and depressive mood as measured by the Beck Depression Inventory was examined in the 31 dialysis patients and the five additional transplant patients who participated in both studies [27]. This revealed a significant positive correlation between pain and depression ( $r = +0.35$ ,  $P < 0.05$ ). For the 31 dialysis patients alone this was true both for pain on dialysis ( $r = +0.55$ ,  $P < 0.01$ ) and pain off dialysis ( $r = +0.4$ ,  $P = 0.01$ ).

**Compliance and pain.** The relationship between compliance and pain in dialysis patients was investigated for both the occurrence and intensity of pain. First, four stepwise discriminant function analyses were performed to try to separate those

who reported headaches or cramps either on or off dialysis from those who did not on the basis of compliance measures. In this case the discriminant function analysis assesses whether or not a series of variables (for example, compliance measures) can classify correctly a qualitative difference in a population (for example, patients who have from those who do not have a specific type of pain). These compliance measures included the means and SD of BUN, inorganic phosphate, potassium and weight change between dialyses. Only for the category of headaches off dialysis was it possible to separate sufferers from nonsufferers on the basis of the compliance data  $\chi^2 = 24.15$ , 12 df,  $P < 0.05$ . The most important compliance measures which contributed to this discrimination were the SD of the BUN and potassium values.

A second type of analysis used MPQ scores in a hierarchical multiple regression analysis entering background covariates at the first step and then investigating whether or not the group of compliance measures was related significantly to pain. Seven different hierarchical multiple regressions were run using the following dependent variables: total pain (equals the sum of MPQ scores for each pain for each patient), total pain on dialysis, total pain off dialysis, total pain on dialysis weighted by the frequency of occurrence of pain, total headache pain on dialysis and off dialysis, and total cramp pain on and off dialysis. In none of these analyses was compliance significantly related to pain. A separate regression analysis investigated the specific relationship between weight gain (average and SD) and cramps on and off dialysis. A smaller variation in weight gain between dialyses (SD) was related significantly to more cramps on dialysis ( $F = 9.08$ ,  $P < 0.01$ ).

**Reliability of diagnosis of dialysis headaches.** The reliability of the diagnosis of dialysis headache was evaluated by calculating the Kappa statistic [28] for each pair of raters and by averaging the Kappas for all the possible combinations of the five raters. Thus, after correcting for chance the five raters agreed on the diagnosis of dialysis headache one third of the time ( $\bar{K} = 0.33$ ). In addition, patients who had headaches on dialysis tended to experience them off dialysis and those not having them on dialysis tended not to have them off (see

**Table 8.** Cross tabulation of occurrence of headaches for dialysis patients on and off dialysis

		No. of patients who report headaches off dialysis	
		No	Yes
No. of patients who have headaches on dialysis	No	18	2
	Yes	13	20

diagonals of Table 8). A sizeable minority of the patients (25%) reported headaches on dialysis but not off.

### Discussion

It is clear from the data that dialysis is not necessarily a painful procedure. Although all of the dialysis patients reported some pain, only one quarter reported significant pain problems. Surprisingly, transplantation was not associated with an overall reduction in pain. It replaced some pains with others and resulted in a longer average duration for cramps, headaches, bone, chest, and back pain. Currently, we are replicating these results in a prospective study; if they are confirmed, they may constitute an important consideration for dialysis patients contemplating a transplant.

Among the different types of pain experienced by dialysis patients, only cramps and fistula pain seem linked directly to the dialysis procedure. Both are infrequent prior to kidney failure or after transplantation relative to their rates on dialysis. Moreover, fistula pain was not reported off dialysis while cramps which were frequent off dialysis occurred almost exclusively the night after a dialysis session.

Our data did not support a separate diagnostic category of dialysis headache for a variety of reasons. First, such a diagnosis could not be made reliably. Second, the prevalence and characteristics of headaches experienced by patients on and off dialysis and after transplantation was similar. Moreover, this prevalence was similar to that reported in general medical practice [29]. Third, the reported characteristics of on dialysis headaches do not differ greatly from those of mixed muscle tension-migraine headaches except that they occur on dialysis. Fourth, the majority of patients tend to have headaches both on and off dialysis or not at all. If these are dialysis headaches it might be useful to search for them in the group (25%) of patients who report headaches on dialysis but not off. At present, our data support the hypothesis that dialysis serves as a nonspecific stressor which may increase the salience of everyday headaches that occur during a dialysis session but does not have any necessary direct effects.

Compliance and pain were not related significantly in this population. This may be due to the generally high levels of compliance or to the lack of association between compliance and pain. Unfortunately, we have not been able to find any published studies with which to compare our data. Prospective daily monitoring of pain and compliance may allow for a more sensitive investigation of this relationship.

Contrary to our prediction, actual degree of control over dialysis was not associated with a reduction in pain. This result seems to conflict with previous pain research and theory [9] and

with the reports of the self-hospital and home care patients we interviewed who strongly believed that their personal control over the dialysis procedure reduced pain. Our data indicating a significant negative correlation between perceived control over dialysis and pain on dialysis points to the importance of perceived as opposed to actual control and may reconcile the apparent contradiction between our data and previous research and theory. Considering the post hoc nature of this analysis it must be treated cautiously; however, it indicates an important direction for future research.

What additional evidence does this study provide concerning the determinants of pain for ESRD patients? Not surprisingly, increased pain is related to poorer physical status. This is true, at least in part, because physician ratings of physical status may have included pain. Currently, we are attempting to develop more reliable measurements of physical status [30] (Hutchison, unpublished manuscript) and investigating to what extent the measurement of pain is independent of physical status. Second, women consistently reported more pain than men. This is not an unusual clinical finding and seems to be related more to pain tolerance than to pain perception [9].

Our data do not provide any evidence concerning the relative efficacy of different types of membranes, delivery systems or types of bath because these were confounded with hospital and type of dialysis. Patients often reported to us that staff change their dialysis equipment, procedures, and medications in an attempt to alleviate pain. Our impression is that after adequate dialysis has been established such changes do not have long-term effects for established pain problems. This impression requires empirical validation.

One of our most suggestive findings concerning the psychological correlates of pain relates to depression. The patients who concurrently participated in both studies showed a positive and significant correlation between depressive mood and pain. Further research is currently investigating the direction of this relationship as well as possible therapeutic implications.

There are several clinical implications arising from these data. First, nephrologists and transplant surgeons should not assume that "dialysis pain" will disappear after successful transplantation. Second, pain during ESRD is not solely a function of medical procedures and physical status but is probably also affected by emotional factors including perceived control and depression. Third, whatever the sources of pain, health professionals working with ESRD patients should begin to consider methods of pain control in addition to medication. Potential methods which are becoming common in most pain clinics include muscular relaxation exercises, hypnosis, and biofeedback. Their success with other medical populations warrants some controlled studies with ESRD patients [9].

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