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ASSESSMENT OF HANDICAP IN CHRONIC DIALYSIS DIABETIC PATIENTS (UREMIDIAB§ STUDY)

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ABSTRACT. As part of a large epidemiological study concerning 494 diabetic patients undergoing dialysis throughout France – the so-called Uremidiab§ study – we collected data with the aim of describing objective as well as subjective aspects of quality of survival. Questionnaires were completed from medical records and from direct interviews by trained collectors. The data included: (a) medical status and impairments; (b) functional status with the Barthel index for basic activities of daily living; (c) subjective aspects through self-estimation of fatigue, pain, care burden, quality of life and working capacity. Only 21% of the patients had type 1 diabetes and more than 71% were currently insulin-treated. Among the various long-term complications registered, visual impairment was a prominent feature: 25% of the patients were blind and the best eye vision scored 0.8 or more for only 20%. The differences found between the two types of diabetes are discussed. As a result of these impairments, functional status was poor even when considering basic activities, with a mean Barthel index (BI) of 80 ± 19. Type 2 patients and those patients undergoing continuous ambulatory peritoneal dialysis had significantly lower BI. The results are discussed in the light of the literature. Compared with a group of 121 non-dialyzed diabetics, patients scored higher for fatigue and pain, but not for care burden and quality of life.

Key words: diabetes, dialysis, handicap assessment.

Although end-stage renal failure is a major cause of death among diabetic patients (1) the length of survival has been improved by techniques of renal replacement. Hence questions have been raised about the quality of survival of chronic dialysis patients (10), questions which could be of particular concern for diabetic patients. We conducted a large study – the so-called Uremidiab§ study – among diabetic patients treated in dialysis centers throughout mainland France. The main goals were: (a) to estimate the prevalence of diabetes in dialysis patients; (b) to get detailed information about the type of diabetes and the natural history of nephropathy (the results of this two-phased study will be published elsewhere) (31); (c) to describe objective and subjective aspects of quality of survival. For the purpose, data was collected on disabilities and handicaps. The present paper deals with this third part of the study.

METHODS

Sample design. In the first phase, among a total of 245 existing centers in mainland France, 198 (81%) dialysis centers gave information about prevalence: 884 diabetic patients were undergoing dialysis among 12,903 dialysis patients, i.e. a prevalence rate of 6.9%. In the second phase, all 63 dialysis centers with more than 3 diabetic patients simultaneously treated were selected. Although the sample was not strictly representative, this selection was necessary for efficiency reasons: indeed in the second phase, each patient of the selected centers was directly visited throughout France. Therefore a total of 494 diabetics undergoing dialysis were fully interviewed.

Data sources. To ensure the quality of the data, 7 residents, responsible for collection, underwent a 3-day training session. The data had to be collected from a standardized questionnaire. This questionnaire was modified and definitively adopted after a test interview by one of the collectors involving 4 local patients. After the patient's informed consent, medical data was collected anonymously from the medical record. Disability assessment as well as socio-familial and employment status were obtained from the patients and/or from the principal caregiver. Subjective indicators were completed from the patient's responses.

Variables. Three categories of variables were analyzed concerning: 1) the description of impairments related to diabetes, end-stage renal (ESRD), long-term complications and care burden; 2) the objective aspects of handicap; and 3) the subjective aspects of perceived illness and quality of life.

Impairments

In addition to the basic data on patients and their medical history, data was collected concerning: type, duration and treatment of diabetes; type and duration of dialysis; prevalence, duration and treatment of retinopathy; current monocular vision at 5 meters; prevalence of ischemic limb disease, prevalence and location of amputations; prevalence of coronary heart disease, stroke, diabetic foot and symptomatic neuropathy.

Objective aspects of handicap

The Barthel Index (22) was used to assess dependency on basic activities of daily living (ADL): item "putting on brace", built for stroke patients, was changed into "injecting Insulin" with the same scoring, as injection could be considered as an ADL for insulin-treated diabetics. A score of 100 was indicative of regular independence of basic ADL, irrespective of difficulty or time to do them. In addition, some instrumental ADL were assessed: dependency on outdoor walking, meal preparation and housekeeping. Each was scored as an ordinal scale (without difficulty, alone but with difficulty, someone's help needed, total dependency). Employment status was analyzed as well as social and financial support for handicap.

Subjective aspects of handicap

Most instruments in use for the assessment of perceived health were too time-consuming (16) for use in this study. Therefore, analogue visual scales were used for gross assessment of fatigue, pain, care burden, quality of life and working capacity. When visual impairment prevented the utilization of visual scale, patients were asked to indicate a notation from 0 to 10. Later the score was converted from 0 to 100 as on visual scales. All scales were ranged from best (scored 0) to worse (scored 100).

Statistics. All data was computed on an IBM-PC and statistics were handled by SPSS. The Student's *t*-test was used for comparisons of means and the chi-square test was used for comparisons of proportions. The Mantel-Haenzel chi-square was used for adjusted analysis. All tests were two-tailed and *p*-values under 0.05 were considered significant.

RESULTS

Among the 494 diayzed diabetic patients 13 with secondary diabetes and 9 with unclassified diabetes were excluded: the characteristics of the remaining 472 diabetic patients interviewed in 63 dialysis centers are summarized in Table I.

Impairments

Twenty-one per cent were type 1 (insulin-dependent) diabetic patients, all under insulin therapy. Among the 374 type 2 diabetics, 239 (64%) were insulin-treated at the time of the interview. Type 2 patients were significantly older and had longer duration of diabetes, whereas the duration of dialysis was not different between the two types. Most patients (89%) had 3 dialysis sessions per week and the mean duration was 9.5 hours per week. Eighty-four per cent had hemodialysis treatment (HD) while 16% had continuous ambulatory peritoneal dialysis (CAPD).

The frequency of the main long-term complications is found in Table II. Retinopathy was found in 77% of all cases, and in all but a single Type 1 diabetic patient. Mean duration of retinopathy was 8 ± 6 years, longer for Type 1 ($p < 0.001$). In order to have an idea of the functional residual vision, we computed the value of the best eye vision (BEV) for each patient. Mean BEV was 0.49 ± 0.34 without any difference between the two types of diabetes. Twenty-five per cent of the patients scored 0.1 or less. Only 20% scored 0.8 or more. Near half of the patients had ischemic limb disease and 18% underwent surgical treatment for that reason. Forty-two patients (9%) were amputed, but a total of 112 amputations was registered, as most patients underwent iterative amputations, even bilaterally for 12 patients. As usual, the more frequent stroke mechanism was ischemia (86%). Coronary heart disease was more frequent in older Type 2 patients, while diabetic foot in addition to neuropathy was more frequent in Type 1.

Table II. *Frequency (in percentages) of long-term complications*

	Total	Type 1	Type 2
Retinopathy	77	99 ($p < 0.0001$)	71
Ischemic limb disease	47	61 NS	51
Coronary heart disease	32	21 ($p = 0.015$)	35
Stroke	16	14 NS	17
Diabetic foot	24	33 ($p = 0.02$)	21
Neuropathy	27	45 ($p < 0.0001$)	22

NS = non significant

Table I. *Characteristics of the 472 dialyzed diabetics*

	Total	Type 1		Type 2
Number of patients	472	98 (21%)		374 (79%)
Age (years)	62 ± 12	46 ± 11	($p < 0.0001$)	67 ± 8
Sex Ratio (M/F)	1.09	1.29	NS	1.04
Duration of diabetes (years)	20 ± 8	28 ± 10	($p < 0.001$)	19 ± 10
Duration of dialysis (years)	3.4 ± 2.8	3.5 ± 2.9	NS	3.3 ± 3.0

NS = non significant.

Table III. *Frequency of dependency (percentages of patients dependent of someone's help)*

	Uremidiab§ patients	>65 y.o. general population (see ref. 7)
Eating	7	–
Indoors walking	12	–
Dressing	17	3–5
Grooming	20	3–6
Injecting Insulin	68	–
Outdoors walking	36	16–25
Preparing meals	46	3–5
Housekeeping	69	10–18

Objective aspects of handicap

Table III indicates percentages of patients needing minimal to maximal help for ADL and other activities assessed. Mean BI was 80 ± 19 (20–100) and 25% of the patients scored less than 70. Table IV shows differences in mean BI according to the type of diabetes (Type 1 vs Type 2) and modality of dialysis (HD vs CAPD). Type 2 patients and those patients undergoing CAPD had significantly lower BI. After creating 2 classes for BI (80 or less vs more than 80) and for age (50 or less vs more than 50), the Mantel-Haentzel adjustment was performed. Age-adjusted odds ratio was not significant for BI between the 2 types of diabetes. However CAPD patients had a significantly higher risk for low BI. No differences were found between incenter and home-treated patients (not shown).

One hundred and seventy-five patients (37%) had retired and 76 (16%) were still at school. Among the 221 remaining patients, only 15 (7%) were workng for pay full-time or part-time, 75% were socially recognized as handicapped through "invalidity card" or "long disease" status. Invalidity card was more frequent in Type 2 (85% of Type 2 vs 29% of Type 1, $p < 0.0001$).

Subjective aspects of handicap

Mean scores on analogue visual scales are indicated in Table V. No differences were found related to the type of diabetes (not shown). Mean scores for fatigue, pain, care burden and alteration of quality of life were compared with those of 121 non-dialyzed diabetic patients enrolled in another survey (2, 4). Significantly higher scores were found with dialysis for fatigue and pain, while self-estimated care burden and quality of life were not significantly different in the two groups (Table V).

DISCUSSION

The main goal of this study was to describe different aspects of handicap in diabetic patients under chronic dialysis in France. The model used was derived from the International Classification of Impairment, Disability and Handicap (30), because of its value as functional assessment methodology for judging needs, planning treatments and allocating manpower and

Table IV. *Mean Barthel index according to type of diabetes and modality of dialysis*

	Type 1	Type 2	HD	CAPD
BI	89 ± 15 ($p < 0.0001$)	79 ± 20	84 ± 18 ($p = 0.005$)	74 ± 25
Age	46 ± 11 ($p < 0.0001$)	67 ± 8	62 ± 12 NS	60 ± 14
OR_A (95% CI)	0.72 (0.29–1.80) NS		2.33 (1.09–5.25) $p = 0.03$	

HD = Hemodialysis; CAPD = Continuous ambulatory peritoneal dialysis; BI = Barthel index: NS = non significant; OR_A = adjusted odds ratios; CI = confidence intervals.

Table V. *Mean score on visual scales: comparison of dialyzed and non-dialyzed diabetics*

	Uremidiab§ patients	Non-dialyzed diabetics (see ref. 4)
Fatigue	55 ± 29 ($p < 0.01$)	40 ± 28
Pain	35 ± 32 ($p = 0.02$)	27 ± 30
Care burden	57 ± 31 NS	52 ± 33
Alteration of quality of life	46 ± 28 NS	46 ± 30
Alteration of working capacity	68 ± 29	not assessed

resources (29). No study was available in France concerning these multidimensional aspects of handicap in chronic dialysis patients. While a large body of literature is available concerning outcome of therapy for dialyzed patients, most of these studies have focused on some particular dimension of handicap (9, 13, 14, 15, 18, 19, 28). Moreover, only a few studies have focused on diabetic patients (12, 15, 24). Yet diabetes is becoming one of the most frequent causes of ESRD (24). In France, the prevalence of diabetes among dialyzed patients was found to be around 7% in our study (31). Although low, compared to many other countries, the incidence is on the increase, especially for Type 2 patients partly due to higher risk patients now being admitted for dialysis (6, 14, 21, 24). The high proportion of Type 2 diabetic patients, who account for 5.4% of the overall dialyzed patients population in our study (31), could be partly due to the severity of the criteria used for definition of Type 1 diabetes, derived from the National Diabetes Data Group's guidelines (23) and from the study by Cowie and al. (8).

Diabetes mellitus *per se* is a major handicap, either by the multiple physical impairments related to degenerative long-term complications or by psychosocial consequences of chronic evolution and care burden. Considering the description of impairments, our population is large enough to be grossly, if not strictly representative. The high prevalence of degenerative complications is noticeable, but in contrast to other studies (12, 24), we focused on impairments rather than clinical or paraclinical semiology. As stated by Grenfell (12), retinopathy is more frequent in Type 1 diabetic patients. However, this could be indicative of a higher proportion of non-diabetic renal disease in dialyzed Type 2 patients (12, 24). Indeed, on the basis of a thorough retrospective examination of the medical reports, we could exclude the responsibility of diabetes in the genesis of nephropathy in 52% of Type 2 patients, compared with only 1% in Type 1 (31). Therefore, a comparison of frequency of complications in the absence of renal biopsy in the two types of diabetics must be stated with caution.

Prominent visual impairment is a considerable functional disability. Concerning blindness, our results are in the same order as those of Grenfell (12). Moreover we found that a large majority of patients had functional visual loss even if not blind. One feature of our study was to provide a measurement of the best eye vision. It was noteworthy that in addition to the blind patients (25%) more than half of the patients were visually impaired. We observed symptomatic neuropathy as well as diabetic foot more frequently in Type 1, while higher frequency of coronary heart disease in Type 2 was probably accounting for the lower survival rate reported elsewhere in Type 2 patients (5, 12, 14).

The Barthel index was used as an indicator of basic autonomy. It was found to be a valid and reliable index of ADL performance, and relevant for assessment of basic personal care needs (11). As 71% of the whole population was Insulin treated during the time of the study, we felt that independence of Insulin injection could be considered as a basic ADL for these patients and could logically replace the "brace-orthosis" item built for stroke patients. While we found no significant reduction of mean BI in our non-dialyzed diabetics (4), the lowering of mean score, found in our study, stresses the dependency of Uremidiab§ patients on basic ADL. Furthermore, one of the 10 items of the BI being related to urinary incontinence, the relative weight of this item (10% of the total score) is markedly over-estimated for our patients, as nearly all of them had no residual diuresis.. Therefore a mean of 82 is certainly indicative of a very poor ADL performance in this population. This points out the need for familial and social support. From another point of view it is obvious that the variable "age" can act as a confounder, especially when comparing the two types of diabetes (Table IV). However, although age-dependent, mean BI is still low in the Type 1 younger population. Furthermore, it is clear that CAPD patients are at higher risk for poorer autonomy, irrespective of their age. Table III shows ADL dependency in Uremidiab§ data as well as in a compilation of several studies of home-living aged-people in France (7). Our patients appeared much more dependent than the general aged population in all ADL we compared. This is also in accordance with Gutman's results which show that 51% of the dialyzed diabetic patients were unable to care for themselves, in comparison to 20% of the non-diabetic dialyzed patients (15). Therefore diabetes seems to heavily hinder rehabilitation of ESRD patients.

Working abilities and vocational rehabilitation have been largely studied in dialysis patients. In Evans's study of 859 patients (9), whatever the cause of ESRD, 37% of the in-center hemodialysis patients considered themselves able to work full-time but only 24% were actually working for pay. The same results

were found in non-diabetic patients by Gutman (15). Considering diabetic patients, our data showed that only 7% of the potentially active patients were engaged in earning work. This is dramatically low when compared to the 28 to 51% reported for the whole dialysis population in a review from Kaplan (19). A low score was reported for self-estimated working capacity and vocational environment in 102 chronic HD patients, but nothing was done about the etiology of renal failure. Physical impairment as well as social support factors could explain this professional handicap.

As in Evans's study (9), we tried to assess some subjective aspects of handicap. Subjective quality of life is a very complex concept which should be analyzed through multidimensional indicators rather than gross analogic visual scales (26). Many studies in this area showed discrepancies between subjective quality of life and what could be expected in view of objective measures on disability (9). When compared to non-uremic diabetic patients, our population showed higher level of fatigue and pain. Fatigue could be closely related to anemia; therefore the therapeutic impact of Erythropoietin on subjective indicators should be assessed (17). These subjective aspects of handicap could be of importance, together with physical impairments, for a decrease of familial and social interactions outlined in several studies (18, 19, 28). However, global QL scores were not different between dialyzed and non-dialyzed diabetics. This conflicting result is also reported by Evans (9) who found no difference between dialyzed patients and general population. We suggest that chronic illness could progressively modify the reference used by the patient for scaling his/her global quality of life.

Therefore, despite poor physical and psychological conditions, patient adjustment to illness remains possible (3). Even if the adjustment to care burden is particularly difficult for dialyzed diabetic patients, this possibility must be taken into consideration in education as well as rehabilitation programs. Rehabilitation must be seen not only as the achievement of physical and working activity (25) but also as the promotion of psychosocial adjustment all over the disease (20, 27).

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REFERENCES

1. Andersen, A. R., Christiansen, J. S., Andersen, J. T., Kreiner, S. & Deckert Y.: Diabetic nephropathy in type I (insulin-dependent) diabetes: An epidemiological study. Diabetologia *25:* 496–501, 1983.
2. Benhamou, P. Y., Borgel, F., Pasquier, B., Bosson, J. L., Halimi, S.: Assessment of well-being in diabetic patients. Diabetologia *33* (suppl): 469A, 1990.
3. Blodgett, C.: A selected review of the literature of adjustment to hemodialysis. Int J. Psychiat Med *11:* 97–124, 1981.
4. Borgel, F., Pasquier, B., Benhamou, P. Y. & Halimi, S.: Evaluation du Handicap chez le patient diabétique. Ann Réadapt Med Phys *33:* 81–86, 1990.
5. Brunner, F. P., Broyer, M., Brynger, H., et al.: Registry report: Survival on renal replacement therapy. Data from the EDTA registry. Nephrol Dial Transpl *3:* 109–122, 1988.
6. Challah, S., Brunner, F. P., Wing, A. J.: Evolution of the treatment of patients with nephropathy by renal replacement therapy in Europe over the decade. Data from the EDTA registry. *In* Diabetes and the kidney (ed. C. E. Mogensen). Boston, Nijhoff Publ., 1988.
7. Colvez, A. Gardent, H.: Les indicateurs d'incapacité fonctionnelle en Gérontologie. CTNERHI-INSERM, PUF, Paris, 1990.
8. Cowie, C. C., Port, F. K., Wolfe, R. A., et al.: Disparities in incidence of diabetic end-stage renal disease according to race and type of diabetes. N Engl J Med *321:* 1074–1079, 1989.
9. Evans, R. W., Manninen, D. L., Garrison, L. P., et al.: The quality of life of patients with end-stage renal disease. N Engl J Med *312:* 553–559, 1985.
10. Freeman, R. B.: Treatment of chronic renal failure: An update. N Engl J Med *312:* 577–579, 1985.
11. Granger, C. V., Albrecht, G. L. & Hamilton, B. B.: Outcome of comprehensive medical rehabilitation: Measurement by Pulses profile and the Barthel index. Arch Phys Med Rehabil *60:* 145–154, 1979.
12. Grenfell, A., Bewick, M., Parsons, V., et al. Non-insulin-dependent diabetes and renal replacement therapy. Diabetic Med *5:* 172–176, 1988.
13. Gross, J. B., Keane, W. F. & McDonald, A. K.: Survival and rehabilitation of patients on home hemodialysis. Ann Intern Med *78:* 341–346, 1973.
14. Gutman, R. A. & Amara, A. H.: Outcome of therapy for end-stage uremia; an informed prediction of survival rate and degree of rehabilitation. Postgraduate Med *64:* 183–194, 1978.
15. Gutman, R. A., Stead, W. W. & Robinson, R. R.: Physical activity and employment status of patients on maintenance dialysis. N Engl J Med *304:* 309–313, 1981.
16. Guyatt, G. H. Jaeschke, R. Measurements of quality of life in clinical trials: choosing the appropriate approach.

In Quality of life assessment in clinical trials (ed. B. Spilker). pp. 37–46. New York Raven Press, 1990.
17. Haines, C. I., Quality of life issues with Erythropoietin. *In* Erythropoietin in clinical applications: An international perspective (ed. M. B. Garnick), pp. 233–257. New York and Basel, Marcel Dekker Inc, 1990.
18. Kaplan De Nour, A. & Shanan, J.: Quality of life of dialysis and transplanted patients. Nephron, *25:* 117–120, 1980.
19. Kaplan De Nour, A.: Psychosocial adjustment to illness scale (PAIS): A study of chronic hemodialysis patients. J Psychosom Res *26:* 11–22, 1982.
20. Kaplan De Nour, A.: Renal replacement therapies. *In* Quality of life assessment in clinical trials (ed. B. Spither), pp. 381–390 New York, Raven Press, 1990: 381–390.
21. Kappel, D. F. & Van Tuinen, M.: Trends in the incidence of treated end-stage renal disease secondary to diabetic nephropathy. Am J Kidney Dis *8:* 234–238, 1986.
22. Mahoney, F. I. & Barthel, D. W.: Functional evaluation: The Barthel Index. Md State Med J *14:* 61–65, 1965.
23. National Diabetes Data Group. Classification of diabetes mellitus and other categories of glucose intolerance. Diabetes *28:* 1057–1079, 1979.
24. Ordonez, J. D. & Hiatt, R. A.: Comparison of type II and type I diabetics treated for end-stage renal disease in a large prepaid health plan population. Nephron *51:* 524–529, 1989.
25. Rennie, D.: Renal rehabilitation: Where are the data? N Engl J Med *340:* 351–352, 1981.
26. Schipper, H., Clinch, J. & Powell, V.: Quality of life: Definitions and conceptual issues. *In* Quality of life assessment in clinical trials (ed. B. Spither pp. 11–24). New York, Raven Press, 1990.
27. Shapiro, F. L., Schwalbach, A.: Rehabilitation: Its implementation and effectiveness in a dialysis setting. J Chron Dis *26:* 613–616, 1973.
28. Strauch, M., Huber, W., Rahauser, G., et al.: Rehabilitation in patients undergoing maintenance hemodialysis: Results of a questionnaire in 15 dialysis centres. Proc Eur Dial Transpl Ass *8:* 28–32, 1971.
29. Wood, P. H. N. & Badley, E. M.: Contribution of epidemiology to health care planning for people with disabilities. *In* Assessment in rehabilitation medicine. (eds. C. V. Grange and G. E. Goesham). Baltimore, Williams & Wilkins, 1986.
30. World Health Organization. International Classification of Impairments, Disabilities and Handicaps. WHO, Geneva, 1980.
31. Zmirou, D., Benhamou, P. Y., Cordonnier, D., et al.: Diabetes mellitus prevalence among dialyzed patients in France (Uremidiab study). Submitted for publication.

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