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FACTORS RELATING TO CARER BURDEN FOR FAMILIES OF PERSONS WITH MUSCULAR DYSTROPHY

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Objective: **To assess the burden on family carers of persons with muscular dystrophy living in their homes and to determine factors contributing to carer burden.**

Methods: **The study included 56 dyads of people with muscular dystrophy and their family carers. The variables for carer burden were compared by logistic regression in 2 carer groups (burden+/burden−).**

Results: **The mean age of the patients with muscular dystrophy was 32.7 years (median 26.7, range 15–65 years) and that of the carers 51 years (median 48, range 30–80 years). The carers reported the care burden using the Zarit Burden Inventory (median score 23, range 0–57/88). Multivariate analysis produced 3 adjusted explicative factors: carer characteristics related to risk of perceived burden are self-report of poor social functioning on the SF-36 (OR = 26.6 (2.6–278); $p = 0.006$), self report of anxiety on the Hospital Anxiety Scale (OR = 7.1 (1.4–36); $p = 0.02$) and being a carer under 48 years of age (OR = 7.8 (1.7–34.5); $p = 0.007$). However, it was difficult to dissociate the different health variables of the carers from each other.**

Conclusion: **This approach should lead to better decision-making by medical teams, patients and their carers.**

Key words: adult, carers, quality of life, muscular dystrophy, disabled persons.

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INTRODUCTION

Neuromuscular disease involves a loss of muscular strength, which is an objective restriction to the abilities of the patient. The degree and severity of loss of strength varies. The characteristics or complications of all neuromuscular diseases include progressive weakness, limb contracture, spine deformity, decreased cardiopulmonary function and, in some, intellectual impairment. These pathologies are classified as rare diseases. They may start at any age. A Swedish population study found an overall prevalence for muscular dystrophy of 39/100,000 inhabitants for some 30 pathological forms described (1). In the absence of any curative treatment, these degenerative diseases are currently dealt with in an essentially palliative manner. However, due to improvements in medical follow-up and care of these patients, life expectancy has increased considerably. As a result, the period of dependency for these patients on their family carers is also lengthening. Despite high levels of dependency, many people with muscular dystrophy live at home, thanks to so-called "informal" carers, who are often relatives. Maintaining a patient in the home is often only possible through the presence of a family member. The health of this main carer who devotes him/herself to the relative with muscular dystrophy in many ways conditions both the duration and the quality of care in the home. Carers have a greater risk of subjectively perceived ill-health and poor health-related quality of life (HRQoL).

In order to improve the quality of life for carers of patients with muscular dystrophy, it is important to explore the interactions within the carer/patient dyad. In establishing an overall care protocol, and as a complement to medical information, it is therefore important to be able to identify environmental or human factors that affect the burden experienced by the carer. Interactions, whether environmental or emotional, that are liable to improve the quality of life of the dyad need to be determined so as to facilitate maintenance in the home for the person with muscular dystrophy, while at the same time avoiding reaching exhaustion point for the carer. Health professionals need to be able to recognize critical situations so as to make medical and social resources available to improve the quality of life of the patient/carer dyad.

No study has attempted to measure the material and emotional care burden in family carers of subjects with muscular dystrophy, and the factors that influence the feeling of burden. Although there is considerable research now available on caring for older people, there is less on burden for carers of younger people. This is probably because muscular dystrophy is a rare condition, but it is important to recognize the burden experienced by carers of people with this condition and to identify ways of assisting them.

This study was designed to assess the care burden for family carers of patients with muscular dystrophy and to identify factors determining the care burden.

METHODS

Data was collected for the period April 2003 to September 2004. It was a single-centre study of family carers caring for patients followed in

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pluridisciplinary consultation in Reims University Hospital. This centre caters for patients with various types of hereditary neuromuscular disease from the Champagne-Ardenne population basin in northern France. All family carers of patients with muscular dystrophy were included consecutively in the study over the period defined. The patients were living at home with their families. There are 1,360,000 inhabitants in the Champagne-Ardenne region. There are 88 people aged 15 years or over in follow-up. Prevalence figures are estimated at 150 cases per million inhabitants (adults and children), which amounts to an expected patient population of 200 (adults and children). On these hypotheses we have approximately 50–60% of patients with muscular dystrophy in follow-up in our area. Of the 88 patients in follow-up, non-included patients were those in institutions or living alone. Thus far, no carer meeting the inclusion criteria has refused to participate in the study; however our sample should not be considered as representative of all family carers.

The patient/carer dyads agreed to participate in the study and their inclusion was conducted according to the Helsinki recommendations. Illiterate patients or those with serious reading difficulties were not included in the study. After an informed consent procedure, the questionnaires were self-administered and completed independently by the patients and the carers at the time of the pluridisciplinary consultation, during which the patients underwent a full clinical examination.

The variables of interest concerning patients with muscular dystrophy are (*i*) the type of muscular dystrophy, (*ii*) the Walton impairment score (2), (*iii*) the degree of dependency for personal care, measured by the Modified Barthel Index (Collin) (3) and the Katz scale (4), (*iv*) the patient's socio-demographic data and (*v*) HRQoL according to the SF-36 (5–7).

The carers were asked to complete a certain number of questionnaires, including the Zarit Burden Inventory (ZBI) (8–10). This is a self-administered questionnaire comprising 22 items with 5 response choices. This instrument was used to measure the burden for carers attending subjects with dementia (11) or hemiplegia (12). The measure has been validated in French, and it assesses the physical and emotional burden experienced by the main carer. The score can range from 0 to 88, with excessive burden being felt when the score is 21 or more. Mental functioning, mental well-being and anxious and depressive symptoms were measured in carers using two HRQoL instruments (the SF-36 and the 12-item General Health Questionnaire- GHQ-12), and an instrument quantifying thymia (Hospital Anxiety Depression Scale – HADS). The GHQ-12 (13–16) assesses mental well-being on a scale where 0–2 = wellbeing and 12 = psychological distress. The HADS (17, 18) estimates the probability of having anxiety symptoms (subscale score $\geq$11/21) and/or depressive disorders (subscale score $\geq$11/21). Socio-demographic data concerning the carer was also collected. Informal assistance was quantified by the number of hours of care-related activities performed by the main carer; the estimation of this assistance on daily and weekly basis concerned any assistance for personal care (washing, dressing and undressing, meals, transfers, various types of care such as tracheostomy care, gastrostomy feeding and care). The weekly hours of formal assistance were also recorded, this referring to outside assistance by persons who were paid. Each carer completed the SF-36 HRQoL questionnaire.

Statistics

Analyses were performed using SAS 8.2 software. The socio-demographic data enabled characterization of the study sample. The variables explicative of burden (anxiety and depression in the carer, hours spent providing personal care, degree of dependency of the subject in care) were compared in 2 groups of carers, a group with a significant burden defined by a Zarit score $\geq$21 compared with a group with no burden felt (Zarit <21) (10, 19). The scores for the 8 domains of the SF-36 were calculated and standardized by subtraction from scores known for the general population in France (according to age group and gender). This produces 2 modes of classification of family carers: the first classification concerns carers obtaining a score differing by less than 20 points from the standardized general population score, which corresponds to a "normal" HRQoL score, and the second concerns carers expressing significant decrease in their HRQoL ($\geq$20 points) (20, 21). A multivariate analysis by logistic regression was performed to study the impact of the different variables potentially explicative of care burden for the carer. The choice of variable entered in the multivariate analysis is motivated by different criteria for the use of logistic regression models.

- The independence of significant variables was checked, using Fisher's exact test (p <0.1) as a screening tool. Then, a full multivariate model was fitted and sets of interrelated variables that caused considerable instability in the model, reflected by unusually large standard errors, were identified. All variables but one in each set of interrelated variables were removed from the model. If such extreme dependence between the explicative factors occurs, then the effect of the interrelated variables cannot be separated, which should be taken into account when interpreting the results.
- The size of the sample, which makes it possible to include 5 independent explicative variables.
- Goodness of fit tests for observed variables with expected variables should yield plausible results (Hosmer Lemeshow test) and the best model is retained.

The 2 classes of the dependent variable are: (*i*) burden absent to slight Zarit score <21, and (*ii*) burden moderate to severe Zarit score $\geq$21. The independent variables applied in this logistic regression model are: age of carer, presence or absence of anxiety measures by the HADS, report or non-report of decrease in HRQoL in social functioning for the carer. The problem of co-linearity between the candidate variables was checked. The mental health variables (SF36), the GHQ12 and the HADS depression and anxiety subscales for the carer are all associated and yield aberrant estimators, so that these scores cannot be dissociated. The HADS anxiety subscale score was chosen since it possessed the strongest association in bivariate analysis with the Zarit score. The age of the subject is associated with the age of the carer (unilateral Fisher's exact test p = 0.03 with a linear tendency). Only the age of the carer is maintained in multivariate analysis (lowest p value in bivariate analysis with Zarit score). On account of sample numbers, 5 variables were retained for multivariate analyses (age of carer, presence/absence of anxiety on HADS scale, report/non-report decrease HRQoL in social functioning for carer, physical mobility of carer, and general health of patient). The 5-variable model does not possess better likelihood ratio than the 3-variable model (Table IV) ($\chi^2 = 35.84 - 29.92 = 5.92$ at 2 ddl = df (degrees of freedom) and p >0.05).

RESULTS

A total of 56 muscular dystrophy patient/carer dyads were studied. Among the patients with muscular dystrophy, 46% were wheelchair users. Table I sums up the characteristics of the study sample. The mean age of the patients (n = 56) was 32.7 years (median 26.7, range 15–65 years) and that of the carers was 51 years (median 48, range 30–80 years). The patients in care had Duchenne's muscular dystrophy (n = 11), Becker's muscular dystrophy (n = 14), Steinert's myotonia (n = 10), facio-scapular-humeral myopathy (n = 5), congenital muscular dystrophy (n = 3), limb girdle muscular dystrophy (n = 4) and spinal muscular atrophy of childhood (n = 5). Four patients had a non-determined neuromuscular pathology. The mean patient score on the Barthel index was 62 (median 80, range 15–100). The carers expressed a mean physical and emotional burden on the ZBI of 23.4 (median 23, range 0–57/88), which is above the validated threshold score, which identifies excessive burden at 22 out of 88. Among the carers, 29 were the mothers, 5 the fathers, 17 were spouses, 3 were friends, 1 was a half-sister and 1 a grandmother. The bivariate analyses (Tables II and III) retained the following independent variables as explicative of the burden felt by carers: the age of the carer (<48; $\geq$48 years), the age of the recipient patient (<26; $\geq$26 years), the degree of dependency of the recipient (Katz, A = independence;

Table I. *Characteristics of the sample of patients with muscular dystrophy and their family carers (n = 56 dyads)*

Characteristics	
Patient gender, *n* (%)	
Men	45 (80)
Women	11 (20)
Patient age (years)	
Median	26.7
Range	15–65
Modified Barthel Index score 0–100	
Median	80
Range	15–100
Duration of disease (years)	
Median	20
Range	4–47
Walton Index, n (%)	
At most 6	29 (52)
More than 6	26 (46)
Carer gender, *n* (%)	
Men	10 (18)
Women	46 (82)
Zarit burden score of carers, *n* (%)	
Zarit <21	26 (46)
Zarit ≥21	30 (54)
Median	23
Range	0–57
Age of family carers (years)	
Median	48
Range	30–80

Walton Index >6 when patient is wheelchair-dependent.

B = dependence for more than 2 activities of daily living (ADL), presence or absence of depression and anxiety in the carer measured by the HADS (<11; ≥11), self-report or otherwise of deterioration in HRQoL (domain scores on SF-36 <20 or ≥ 20 compared with standard values for the French population: patient scores for the SF-36 domains physical pain and perceived health, and carer scores for the domains social functioning, bodily pain and physical functioning). The multivariate analysis (Table IV) yields 3 adjusted explicative factors associated with perceived burden (–2 log-likelihood = 47.4; Hosmer-Lemeshow goodness of fit model $p = 0.7$): perception of poor social functioning on the SF-36 (OR = 26.6; $p = 0.006$), the carer being under 48 years of age (OR = 7.8; $p = 0.007$) and state of anxiety on the HADS anxiety scale (OR = 7.1, $p = 0.02$).

DISCUSSION

In a pragmatic perspective of improving the QoL of these patients, their families also need to be involved, since they can play a part in improving or aggravating this QoL. The care plan for persons with muscular dystrophy needs to integrate the patient/carer dyad. The present study shows a considerable perceived physical and emotional burden for a fairly large proportion of the carers ($n = 30$) as measured by the ZBI. Moreover, there is a simple criterion that can enable identification of the sub-group of carers with a significant care burden: self-report on social functioning on the SF-36 HRQoL scale. The way in which social functioning is perceived by family carers is predictive of burden. The emotional status of the carer measured by the HADS anxiety subscale is also associated with carer perceived burden in this study. It can also be noted that no link has been demonstrated in this investigation study between physical dependency, patient characteristics, or the level of formal assistance provided, and the carer burden.

This research highlights practical implications in designing care plans, with respect both to patients and to family carers. Two rapid, self-administered measures (the social functioning domain of the SF-36 and the HADS) make it possible to identify family carers who are at risk from exhaustion in replacement of the 22 items of the Zarit score. The results show that carers of severely dependent subjects feel a significant burden in relation to restrictions on their psycho-social roles. These results should lead to adjustments in the way the patient/carer dyad is catered for.

Studies (22, 23) using directed interviews of carers of patients with muscular dystrophy have highlighted difficulties that are in line with the psychosocial explicative factors found by the present study: (*i*) negative psychological reactions (anxiety, uncertainty, coping with the patient's functional losses, loss of normal lifestyle and social relationships, fear of sudden deterioration of the patient, distress and difficulty in accepting that the disease is degenerative and leads to increasing dependency); (*ii*) difficulty in gaining access to appropriate healthcare resources that are required (lack of support and advice, lack of care co-ordination or care suited to the patient's condition, difficulty in obtaining access to respite care for carers); and (*iii*) coping with difficulties in daily care procedures.

Some authors (24, 25) have explored the impact for patient/carer dyads of membership of a patient support group. Van Hagstregt et al. (24) have shown a positive relationship between psychological well-being and active membership of a support group. Here the beneficial effect is explained by the increased contacts with other patients, rather than with the nature or the amount of information derived. However, advice and information facilities are viewed by patients and carers as important. In another study by Trojan (25), a decrease of 50–70% in mental stress was observed among patients taking part in organized activities in a support group. Only 1–4% of patients reported a negative impact on psychological well-being. Contacts generated by the group provide greater opportunities for social support for the patient/carer dyad.

In the study sample, age ≥48 years is a protective characteristic for care burden. Older carers express a lesser burden on the ZBI than do younger individuals. It can be suggested that experience in problem-solving strategies in daily life is greater among the older carers. Such strategies can develop from previous failure or frustration. Carers need to learn to remain calm in crisis situations, and experience in this field is probably a favourable characteristic among older carers. The older carers are also often active members of support groups for the particular pathology, and attending such groups has enabled them to talk about care strategies with other carers, and to be less isolated following loss of contact with friends and family. The younger carers are less tolerant of their perceived burden. This has already been shown in

Table II. *Influence of patient characteristics on the degree of care burden perceived by carers*

	Zarit burden score (No. of patients)		OR (95% CI) Statistical significance
	Slight burden <21	Moderate burden ≥21	
Gender			
Men	20	25	1.5 (0.4–5.6)
Women	6	5	$p=0.6$
Age			
<26 years	8	20	4.5 (1.5–13.9)
≥26 years	18	10	$p=0.007$
Katz ADL			
A	13	12	1.5 (0.5–4.3)
B	13	18	$p=0.5$
Duration of disease			
≤10 years	5	3	1 (0.97–1.1)
>10 years	21	27	$p=0.5$
Wheelchair use			
Walton ≤6	14	15	1.1 (0.4–3.1)
Walton >6	12	14	$p=0.9$
Educational level			
<Baccalaureate	13	19	0.6 (0.2–1.7)
≥Baccalaureate	13	11	$p=0.3$
Patient SF-36			
PF			
<20 points	6	2	3 (0.5–16.7)
≥20 points	20	20	$p=0.3$
RP			
<20 points	12	12	1.1 (0.4–3.2)
≥20 points	14	15	$p=0.9$
BP			
<20 points	19	14	3.5 (1.02–12.2)
≥20 points	5	13	$p=0.05$
VT			
<20 points	12	13	1.1 (0.4–3.2)
≥20 points	12	14	$p=0.9$
SF			
<20 points	18	13	2.6 (0.9–7.9)
≥20 points	8	15	$p=0.09$
RE			
<20 points	14	16	1 (0.3–2.8)
≥20 points	11	12	$p=0.9$
MH			
<20 points	19	20	1.3 (0.4–4.3)
≥20 points	6	8	$p=0.7$
GH			
<20 points	13	6	4 (1.2–13.1)
≥20 points	12	22	$p=0.02$

PF = Physical functioning; RP = Role physical; BP = Bodily pain; VT = Vitality; SF = Social functioning; RE = Role emotional; MH = Mental health; GH = General health.
Interpretation of scores on domains in the SF-36 <20 points =corresponds to little clinical change in QoL domain considered; ≥20 points corresponds to a clinical change in the QoL domain considered; Katz ADL: A =independence for personal care; B =dependence for more than 2 ADL; OR: odds ratio; 95% CI: 95% confidence interval.

other pathologies (26). Other explanations that have been suggested are the demands of the older carers with other life roles at an earlier age, especially for women. The relationship between older age and less burden is due to oldest carers being volunteers and motivated to invest in giving assistance.

Certain authors have studied the effects of "environmental barriers" (factors relating to the home environment) on the incidence of low back pain occurring in mothers who provide regular care for a child with Duchenne's muscular dystrophy. Physical pain can have a negative impact on the carer relationship (27). The pluridisciplinary team in charge of subjects with muscular dystrophy has a part to play in relation to the patient, but also in relation to the family carers. For this purpose it is important to integrate the care project relating to the patient and that relating to the carer.

As in other chronic disabling pathologies, family carers take on this task at the cost of their own health, and their social and professional life. For other pathologies, it has been recognized that there is an increase in their consumption of care and medication in relation to controls (28, 29).

Table III. *Influence of family carer characteristics on burden perceived by carers*

	Zarit burden score (No. of patients)		OR (95% CI)Statistical significance
	Slight burden <21	Moderate burden ≥21	
Gender			
Men	6	4	0.5 (0.1–2.1)
Women	20	26	$p=0.5$
Age			
<48 years	7	21	6.3 (2–20.4)
≥48 years	19	9	$p=0.001$
Health problem			
No	19	14	3 (1.007–9.6)
Yes	7	16	$p=0.05$
Time spent on informal assistance			
<3 hours per day	17	21	1.4 (0.5–4.3)
≥3 hours per day	8	9	$p=0.8$
Educational level			
<Baccalaureate	20	19	2.6 (0.7–9.8)
≥Baccalaureate	4	10	$p=0.5$
Mental Health GHQ-12			
<3	25	19	14.5 (1.7–122)
≥3	1	11	$p=0.01$
Anxiety HADS			
<11	22	16	4.8 (1.3–17)
≥11	4	14	$p=0.01$
Depression HADS			
<11	25	24	NA
≥11	0	6	$p=0.03$
Carer SF-36			
PF			
<20 points	24	17	9.2 (1.8–46)
≥20 points	2	13	$p=0.003$
RP			
<20 points	23	17	5.9 (1.4–23.9)
≥20 points	3	13	$p=0.009$
BP			
<20 points	22	16	4.5 (1.2–16.3)
≥20 points	4	13	$p=0.02$
VT			
<20 points	24	18	8 (1.6–40.3)
≥20 points	2	12	$p=0.005$
SF			
<20 points	25	16	21.9 (2.6–183)
≥20 points	1	14	$p=0.0001$
RE			
<20 points	19	14	3.1 (1.007–9.6)
≥20 points	7	16	$p=0.05$
MH			
<20 points	26	17	NA
≥20 points	0	9	$p=0.002$
GH			
<20 points	24	20	4.8 (0.9–25.2)
≥20 points	2	8	$p=0.08$

PF = Physical functioning; RP = Role physical; BP = Bodily pain; MH = Mental health; RE = Role emotional; SF = Social functioning; VT = Vitality; GH = General health. Interpretation of scores on domains in the SF-36 <20 points = corresponds to little clinical change in QoL domain considered; ≥ 20 points corresponds to a clinical change in the QoL domain considered; GHQ-12 assesses mental well-being on a scale where 0–2 = wellbeing and 12 = psychological distress. HADS estimates the probability of having anxiety symptoms (subscale score ≥ 11/21) and/or depressive disorders (subscale score ≥11/21); OR = odds ratio; 95% CI = 95% confidence interval; NA = OR calculation is not applicable for variable considered

The Swedish authors Natterlund & Alhstrom (30) assessed the opinions of 37 people with hereditary muscular dystrophy followed over 18 months within a multidisciplinary rehabilitation programme. This team specialized in catering for patients with muscular dystrophy, found results that were similar to and complemented those of the present study. In the light of the

Table IV. *Explicative factors for material and emotional care burden for family carers: multivariate analysis by logistic regression according to likelihood ratio method*

	R^2 Cox and Snell	R^2 Nagelkerke	Goodness-of-fit Hosmer-Lemeshow test
Dependent variable (ZBI)			
Burden absent to slight <21			
Burden moderate to severe ≥21	0.41	0.55	$p = 0.74$
Explicative factors	B (SE)	OR	p
Age of family carer (years)*			
<48 years			
≥48 years	2.1 (0.74)	7.8 (1.7–34.5)	$p = 0.007$
Social functioning (SF-36 for carers)			
<20 points			
≥20 points	3.3 (1.2)	26.6 (2.6–278)	$p = 0.006$
Anxiety HADS†			
<11 points			
≥11 points	1.96 (0.84)	7.1 (1.4–36)	$p = 0.02$

*Due to strong correlation, the effect of age of carer could not be separated from the effect of age of person under care.
†Due to strong correlation, the effect of anxiety could not be separated from the effects of the mental and general health of the carer (SF36 and GHQ12).
B (SE) = beta standard error; ZBI = Zarit Burden Inventory; HADS = Hospital Anxiety Depression Scale.

present results and those in the literature (31), several important points emerge for support of carers: (*i*) easier access to a care co-ordinator; (*ii*) control of the patient's symptoms; (*iii*) including the patient in a personalized daily living and care programme; (*iv*) support for carer QoL; (*v*) provision for respite care; (*vi*) accompaniment and assistance for families in their decisions on an overall care programme adapted to the progression of the disease; (*vii*) informing the healthcare team, the carers and the patients to foster better understanding of the disease and its consequences; (*viii*) encouragement of active participation by patients and their families in support groups.

The transition from childhood to adulthood appears to be a key moment for re-assessing needs for support, for information and for re-organization of care. As in the present study, Bothwell et al. (32) have shown that families caring for older children put priority on the need for psycho-social support. According to the parents, moral support is the need requiring most attention. These authors questioned 31 families on their expectations with regard to the care facility where their children with Duchenne's muscular dystrophy were catered for. This Canadian study showed that the parents of the younger children (<6 years) wanted the medical team to prolong the period during which the child was able to walk as far as possible, while the carers of older children (≥6 years) predominantly ask for psychological assistance to cope with anxiety, withdrawal, depression and social isolation (for both the carer and the patient). For older children, families also want information on the risks of assisted ventilation, and support to enable financial independence of the patient. The nature of medico-social support to the families and carers needs to change as the disease progresses.

The lack of power of the present study is one of its weak points. The small sample size limits the number of exploitable explicative factors in multivariate analysis. The threshold of 20 points compared with expected values in the general population is a score considered to be specific when HRQoL scores are interpreted at individual level (33). The option was to retain the specific thresholds for scores, both Zarit and HRQoL. Certain variables are multicollinear and cannot be dissociated one from the other in analysis of results: mental health scores (GHQ12, Mental health of carer – SF36, the depression subscale on the HADS), and also the age of the carer, which is related to the age of the patients in a manner tending towards linearity. When potentially explicative variables were found to be associated with one another or when they gave rise to aberrant estimators, the choice was made to introduce the variable with the lowest p-value in bivariate analysis into the multivariate model. The logistic model used probably explains only part of the perceived burden. Other explicative criteria need to be looked for. It might prove interesting to assess the social and family network, the motives for ensuring care (affective bonds), the living conditions (habitat, local service availability, etc.), the way in which the support provided is determined, the amount of information received by the carer, and how the financial burden is met. A further limitation of the study is common to most carer research: the lack of a point of comparison between carers and non-carers on the carer burden index.

In conclusion, several issues need to be addressed in any global care plan that is to involve the patient and the carer: recognition that people close to the patient are likely to become exhausted, accompaniment in seeking appropriate adjustments (such as appropriate psychological support for development of coping strategies), adequate advice on matters such as respite care or transitory formal assistance, environmental adaptations to favour social functioning within the carer/patient dyad, information and training facilities.

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