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▶ **To cite this version:**

Marie-Christine Rousseau, Karine Baumstarck, Tanguy Leroy, Cherazad Khaldi-Cherif, Catherine Brisse, et al.. Impact of caring for patients with severe and complex disabilities on health care workers' quality of life: determinants and specificities. Developmental Medicine and Child Neurology, 2017, 10.1111/dmcn.13428 . halshs-01562425

HAL Id: halshs-01562425
https://shs.hal.science/halshs-01562425

Submitted on 14 Jul 2017

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Impact of caring for patients with severe and complex disabilities on health care workers' quality of life: determinants and specificities

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PUBLICATION DATA
Accepted for publication 15th February 2017.
Published online

ABBREVIATIONS

HCW	Health care worker
QoL	Quality of life

AIM Individuals with severe and complex disabilities, defined by a combination of profound intellectual impairment and serious motor deficit resulting in extreme dependence, often remain in hospital or at residential facilities. The aim of this study was to identify the determinants of quality of life (QoL) of 238 health care workers (HCWs) caring for individuals with severe and complex disabilities.

METHOD We conducted a cross-sectional study. The recruitment of the HCWs was performed in five French centres specializing in patients with severe and complex disabilities. The selection criteria were age above 18 years, being an institutional referent HCW (a resource person coordinating various issues for or about the patient), and agreeing to participate. Sociodemographic, health, professional variables, and psycho-behavioural (QoL, burn-out, and coping strategies) data were collected.

RESULTS Of the 362 eligible HCWs, 65.7% returned the questionnaires. The scores of the physical and social dimensions of QoL were significantly lower, and the score of the psychological dimension significantly higher, than those of a comparison group. The main factors modulating QoL were age, financial difficulties, nature of coping strategy, and burn-out.

INTERPRETATION This research provides preliminary evidence that caring for patients with severe and complex disabilities affects the QoL of HCWs. These results support the need for optimization of the work environments for HCWs.

Polyhandicap is a condition of severe and complex disabilities corresponding to a chronic disorder occurring in an immature brain, leading to a combination of a profound intellectual impairment and a serious motor deficit, and resulting in an extreme restriction of autonomy and communication.[1] This definition was adopted by the French scientific community and by French law (number 89–798, 27 October 1989, health policy of care disability). The term polyhandicap is close to the notion of profound intellectual and multiple disabilities, which is used in other countries but does not systematically refer to a disorder affecting an immature brain. These polyhandicap patients are completely dependent on human and technical assistance.[2] In many cases, these patients remain in hospital or at residential facilities throughout their lives, and most (up to 60%) of them die in specialist rehabilitation centres.[1] Caring for persons with severe and complex disabilities requires being able to cope with completely dependent patients and to address ethical and distressing concerns.

Psychological distress, stress, burn-out, and quality of life (QoL) have previously been described in different specific categories of health care workers (HCWs), such as those working in critical care units,[3] oncology,[4] among individuals with dementia,[5] obstetric nurses,[6] neonatal units,[7] and mental health nurses.[8] Few data are related to HCWs working in disability institutions.[9–11] We hypothesized that these HCWs, dedicated to providing care for patients with severe and complex disabilities, have to face a specific context that includes frequent physical tasks because of the complete physical dependence of the patients (e.g. frequent moves between places), personal issues and difficult family situations, and restricted

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feedback and recognition of the care due to limitations of communication with the patient and family distance. Knowledge about QoL and its determinants for these HCWs is lacking. Several of these determinants might assist health establishment managers and care teams in choosing appropriate targeted actions.

The aims of this study were as follows: (1) to assess the QoL of a large French cohort of HCWs caring for individuals with severe and complex disabilities in five specialized centres; (2) to measure their QoL against a French age- and sex-matched comparison group; and (3) to identify the potential determinants of QoL.

What the paper adds

- Quality of life (QoL) of health care workers caring for individuals with severe and complex disabilities.
- Determinants of QoL for health care workers include age, financial difficulties, nature of coping strategy, and burn-out.

METHOD

Design and settings

We conducted a cross-sectional study. The recruitment of HCWs was made in five French centres specializing in caring for patients with severe and complex disabilities through the French national polyhandicap cohort. Four of the five centres receive inpatients needing heavy medical care for long durations (many days, months, and sometimes years) through conventional hospitalization stays (specialized re-education centres) and the fifth centre receives inpatients and outpatients needing less heavy medical care (a residential facility).

General organization of the cohort

This cohort was constituted on 1 March 2015, and involved inpatients with severe and complex disabilities who were cared for at five centres, including four re-education centres and one residential facility. The general aim of the cohort study was to identify the impact of potential (socioeconomic, environmental, epidemiological) determinants on the health status of the patients and the daily life of their (natural and institutional) caregivers (NCT02400528). Three different populations were eligible: (1) patients with severe and complex disabilities defined by the combination of motor deficiency (tetraparesia, hemiparesis, paraparesia, extra pyramidal syndrome, cerebellar syndrome, neuromuscular problems) and profound intellectual impairment (IQ<40) associated with everyday life dependence (Functional Independence Measure [FIM]<55), and restricted mobility (Gross Motor Function Classification System levels III–V); (2) familial referents of the included patients (French legal definition of this kind of patient, represented by parents in most cases, or siblings, or others); and (3) institutional HCWs of the included patients. The present study focused on the institutional referent HCWs. In each centre, members of the steering committee who led the survey (consisting of physicians caring for persons with severe and complex disabilities, epidemiologists, and psychologists) held meetings with all HCWs to explain the objectives and modalities of the study.

Selection criteria

The selection criteria for HCWs were as follows: age above 18 years; being an institutional referent HCW of at least one patient who was included in the cohort of patients with severe and complex disabilities (a referent HCW is designed by the health care team for each patient; the referent HCW is the resource person who has to coordinate various issues for and about the patient, such as management care, family contact, administrative and social issues); and agreeing to participate. The non-inclusion criterion was refusal to participate.

Data collection

A self-report booklet was given to each referent HCW volunteering to participate. No specification was given about where they had to fill out the booklet (at the hospital or not). The booklet included the following data. (1) Sociodemographics and health: sex, age, marital status, children, educational level, perceived financial situation, notion of a disabled person living at home, and chronic disease(s). (2) Professional situation: job categories (technical: nurses, physiatrists, psychomotor therapists; basic care: nurse aide; education care: educators), work schedule (full-time, part-time), years of experience in care for patients with severe and complex disabilities, years of experience in the present centre, notion of specific professional formation for patients with severe and complex disabilities, and nature of the centre (re-education centre, residential facility). (3) Psycho-behavioural data: QoL, burn-out, and coping strategies were assessed using self-administered standardized questionnaires. All the details are provided in Appendix S1 (online supporting information).

Ethics

Regulatory monitoring was performed in accordance with the French law that requires the approval of the French ethics committee (Comité de Protection des Personnes Sud Méditerranée V, 20/10/2014, reference number 2014-A00953-44). A written consent form was collected for each participant.

Statistics

The quantitative data are expressed as the means and standard deviations (SD) or the medians and interquartile ranges, and the qualitative data are expressed as numbers and percentages. The World Health Organization Quality of Life (WHOQOL) scores of the HCWs were measured against those obtained from a French age- (six classes) and sex- (females/males) matched comparison group from a sample of 16 392 healthy individuals.

The burn-out total score was computed using the scoring of the developers. The scores of coping were provided in four scores corresponding to a four-factor structure. Comparisons of the mean QoL scores between the different subgroups

(sex, marital status, children, educational level, self-perceived financial status, living with a person with disability, chronic disease[s], job categories, work schedule, and nature of the structure) were performed using Student's *t*-tests and analysis of variance. Associations between the QoL scores and the continuous variables (age, years of care experience of patients with severe and complex disabilities, years of experience in the present centre, coping scores, and burn-out total score) were analysed using Pearson's correlations. Multivariate analyses using multiple linear regressions were performed to identify the variables linked to the QoL scores. In the models, each QoL dimension score was considered to be a separate dependent variable. The independent variables relevant to the models were selected from the univariate analysis, based on a threshold *p*-value of less than or equal to 0.20. The final models produced standardized beta coefficients, which represent a change in the standard deviation (SD) of the dependent variable (QoL score) resulting from a change of one SD in the various independent variables. Independent variables with higher standardized beta coefficients were those with a greater relative effect on QoL. The statistics were analysed with SPSS software (IBM SPSS PASW Statistics Inc., Chicago, IL, USA). All tests were two-sided. The threshold for statistical significance was set at $p<0.05$.

RESULTS

General characteristics of the sample

Between March 2015 and February 2016, a total of 335 questionnaires (with a prepaid return envelope) were proposed to referent HCWs of the five centres. During this period, 238 HCWs returned the questionnaires: the response rate was 65.7% (from 50%–80% according to the centre; the residential facility had the lowest participation rate). The 97 non-participants did not differ from the 238 participants in terms of their mean age and sex.

The participants were between the ages of 21 to 62 years, and 183 (79%) of them were females. Eight per cent reported living with a person with a disability. Twenty per cent mentioned having at least one chronic disease: 10 (20%) cardiovascular disease, 10 (20%) asthma, eight (16%) musculoskeletal troubles, five (10%) immune diseases, four (8%) thyroid problems, three (6%) diabetes, and 10 (20%) other health problems. Most (71%) of the HCWs were classified in the category of basic care (nurse assistants), 18% in the technical care category (nurses, physiatrists, psychomotriciens), and 10% in the education category (educators). The median experience in the present structure and the median experience around persons with severe and complex disabilities were 8 years (interquartile range 4–16y) and 10 years (interquartile range 5–19y) respectively.

The main characteristics are summarized in Table SI (online supporting information).

QoL, burn-out, and coping strategies

The QoL scores are provided in Figure 1. Of the three dimensions of the WHOQOL for which French norms are available compared with age- and sex-matched healthy individuals, the scores of the physical and social dimensions among the participants were significantly lower, and the score of the psychological dimension was significantly higher. Forty-two per cent of the HCWs reported a high burn-out level according to the Maslach Burnout Inventory. The strategies that were based on social support and avoidance were the least used, and the strategies based on problem-solving were the most-used. Details are provided in Table SI.

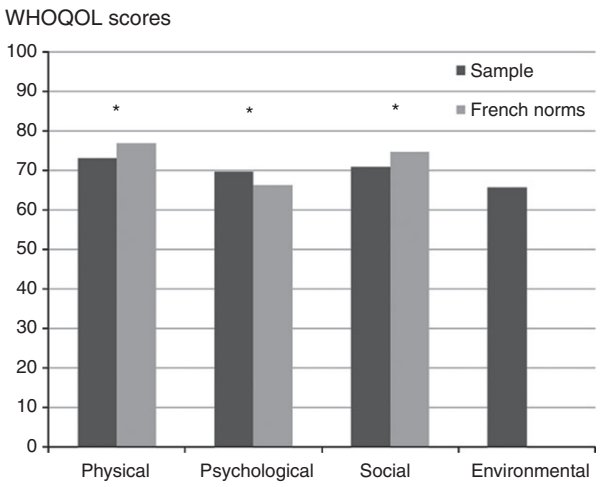


Figure 1: Comparisons of World Health Organization Quality of Life (WHOQOL) scores between the participants and French age- and sex-matched norms.[25] The higher the scores, the higher the quality of life. *$p<0.05$.

Factors modulating the QoL of HCWs

The results for the factors modulating the QoL of the HCWs from the univariate analysis are provided in Table SII (online supporting information). Being older correlated with a lower physical and psychological QoL. Non-single participants reported higher social and environmental QoL scores than single participants. A self-perception of financial difficulties, living with a person with a disability, suffering from a chronic disease, and working part-time were associated with lower QoL scores. The QoL scores did not differ according to sex, children, educational level, and job category. The QoL scores did not correlate with the experience in the specialized structure and the experience among patients with severe and complex disabilities. The use of problem-solving and positive thinking were positively associated with higher QoL scores. High burn-out was negatively correlated with all of the scores.

After adjustment (see Table I), the factors modulating the QoL were as follows. (1) Alteration of the physical QoL dimension: being older ($\beta=-0{,}176$, $p=0{,}003$), reporting financial difficulties ($\beta=-0.161$, $p=0.006$), living with a disabled person ($\beta=-0.152$, $p=0.01$), having a chronic disease ($\beta=-0.146$, $p=0.014$), part-time work schedule

Table I: Determinants of health care workers quality of life (multivariate analysis)

	Physical		Psychological		Social		Environment	
	β	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Age	−0.176	**0.003**	−0.203	**0.002**	−0.052	0.458		
Marital status (0 single, 1 not single)			0.011	0.857	0.063	0.378	0.026	0.658
Children (0 no, 1 yes)			0.130	0.057				
Financial difficulties (0 no, 1 yes)	−0.161	**0.006**	−0.209	**<0.001**	−0.111	0.116	−0.442	**<0.001**
Disabled person at home (0 no, 1 yes)	−0.152	**0.010**	−0.006	0.923			0.085	0.144
Personal chronic diseases (0 no, 1 yes)	−0.146	**0.014**	−0.047	0.415				
Job categories								
Educator (0)								
Technical care (1)			−0.255	**0.008**				
Medical care (2)			−0.083	0.385				
Work schedule (0 full-time, 1 part-time)	−0.166	**0.006**	−0.083	0.178			−0.100	0.093
Nature of structure (0 re-education, 1 residential facility)							−0.159	**0.006**
Coping								
Social support					0.103	0.152		
Problem-solving	0.104	0.148	0.070	0.321	0.010	0.904	0.006	0.929
Avoidance			−0.305	**<0.001**	−0.153	**0.037**		
Positive thinking	0.059	0.390	0.306	**<0.001**	0.118	0.150	0.116	0.092
Burn-out								
Total score	−0.333	**<0.001**	−0.121	0.061	−0.119	0.122	−0.221	**0.001**

β, beta standardized coefficient. Values in bold type, $p<0.05$.

($\beta=-0.166$, $p=0.006$), and burn-out ($\beta=-0.333$, $p<0.001$). (2) Alteration of the psychological QoL dimension: being older ($\beta=-0.203$, $p=0.002$), reporting financial difficulties ($\beta=-0.209$, $p<0.001$), technical care category ($\beta=-0.255$, $p<0.008$), use of avoidance as a coping strategy ($\beta=-0.305$, $p<0.001$), and the non-use of a positive thinking strategy ($\beta=0.306$, $p<0.001$). (3) Alteration of the social QoL dimension: use of avoidance as a coping strategy ($\beta=-0.153$, $p=0.037$). (4) Alteration of the environmental dimension: reporting financial difficulties ($\beta=-0.442$, $p<0.001$), working in a residential facility ($\beta=-0.159$, $p=0.006$), and burn-out ($\beta=-0.221$, $p=0.001$). Marital status, having children, and use of social support and problem-solving for coping were not associated with the QoL scores.

DISCUSSION

While stress and burn-out of HCWs have largely been explored in the literature,[6–10,12,13] there are few studies about the QoL of HCWs. A survey among nurses caring for children in a persistent vegetative state showed that they were enduring conflicting emotions and were suffering mental distress.[14] Other studies have shown a deterioration of QoL in general and in psychiatric nurses.[8,15] Several studies have been performed on natural caregivers of patients with cerebral palsy.[16,17] In this work, we assessed, for the first time, the QoL in a sample of French HCWs caring for patients with severe and complex disabilities.

The first interesting finding of our study is the combination of the negative and positive aspects of caring on the QoL of HCWs. First, our study reported a significant lower physical score than the French comparison group. Even if the centres dedicated to these patients are specifically equipped to face dependency, with an average patient/health worker ratio close to 1/1, the complete dependence of the patients leads to heavy care, with a need to mobilize the patients several times each day (caring, moving, positioning patients in orthotic devices, etc.). Musculoskeletal damage, reported by a fifth of our participants, has been previously well documented among health workers caring for dependent persons.[18] Care of these highly dependent patients probably requires more important technical (patient transfer aids) and human aid (higher HCW/patient ratio).

Second, our study showed a higher psychological QoL for our institutional caregivers compared with French norms. While these HCWs are faced with individuals with very precarious health and social conditions, we hypothesize that working near persons with severe and complex disabilities may help to 'grow in a variety of ways', relativize the annoyances of everyday life, and contribute to feeling their actions as being meaningful, contributing to a satisfactory self-esteem and psychological well-being. The positive effect of caregiving for the natural (non-institutional) caregivers was also described.

Third, the social QoL score of our sample was lower than the comparison group. Some hypotheses should be mentioned. Working near people with very little communication ability, unable to express their approval or disapproval, their feelings or their contentment, may generate a feeling of frustration for the HCW. Caring for a person with severe and complex disabilities is probably a difficult experience to share with the social circle owing to the stigma.[19] The patient with severe and complex disabilities remains stigmatized in our society because of the incurability of these disabilities in a society marked by the medical model of healing and the dimorphic appearance of the patients (joint deformities, major scoliosis, and atypical appearance) that may contribute to a negative impact on

the social dimension. Understanding the mechanisms of stigmatization may define actions to fight against it. The recovery model developed in psychiatry might be rewarding in this area because it represents an alternative to the dominant medical model, by supporting most of the 'anti-stigma' measures with a coherent, optimistic perspective.

The second part of our findings relates to the QoL determinants. A study of the determinants of QoL may be useful in identifying HCWs requiring more attention in their management. For the sociodemographic and socioeconomic determinants, the self-perception of financial difficulties is a strong factor in the modulation of the QoL,[20] compared with other traditional indicators. The specificity of our sample, including only workers, makes it relatively homogeneous; sex, marital status, and educational level, often identified as QoL determinants,[15] were less discriminant in this specific case. Older age was significantly associated with worse physical and psychological QoL dimensions, consistent with the literature. As expected, suffering from a chronic disease altered the physical QoL. The physical dimension was also deteriorated for the individuals (more than 7% in the present study) who mentioned they lived with a person with a disability, which may be explained by the dual (institutional and natural) role. For the professional factors, the experience of individuals with severe and complex disabilities and/or the duration of work in the present structure were not linked with the self-reported QoL, while some studies previously demonstrated that nurses who have a friendship network of a high density in their workplace experience a lower level of stress.[21] As documented previously,[22] working part-time was linked to a lower QoL. Working part-time is sometimes associated with a lower income and is the consequence of a busy family occupation.

More interestingly, the nature of the coping strategies used played a consequential role in the QoL modulation of the individuals. Using active coping strategies, such as positive-thinking, was associated with a higher QoL, while using coping strategies based on avoidance was associated with a lower QoL. A systematic assessment of the coping styles is encouraged to identify individuals who do not use healthy coping strategies. Psychological interventions, such as cognitive training and psychosocial support, psychoeducation and cognitive behavioural therapy, may serve as important additions to rehabilitation and maintain a stable QoL.[23] The important proportion of individuals with a high level of burn-out should alert us and future studies should explore this and its determinants more specifically. The feedback to health managers and health care decision makers will be essential in choosing ways of implementing, organizing, and providing new management strategies.

Strengths and limitations

The representativeness of our sample should be discussed. The five centres allowed a satisfactory representation of the French health care system because they are a large proportion of the structures dedicated to the care of this population at a national level. Our population of HCWs were mostly female, as nurses and nurses' assistants are usually female professions. The age range and sex ratio were in accordance with the French worker population (Âge et conditions de travail dans les établissements de santé Insee 2006, https://www.insee.fr/fr/statistiques/1371967?sommaire=1372045). They were mostly full-time HCWs and experienced care workers. The similarity in age and sex ratios between the participants and the non-participants ensured a satisfactory picture of French HCWs in the field of patients with severe and complex disabilities.

Some determinants, such as the severity and complexity of the disabilities and the patient's age, were not assessed and should be taken into account in future studies. It has been shown that emotional status, emotional intelligence, and spirituality may modulate self-reported QoL.

Further exploration should be performed to explain the low response rate in the residential facility compared with the other centres and, especially, to understand whether these findings are linked to the absenteeism rate.

Longitudinal studies provide more valid information than cross-sectional studies and are necessary to more accurately determine the weights of the potential determinants of QoL. The selection process of the candidate variables for the multivariate models was based on an arbitrary threshold p-value (0.20). Lower thresholds should fail to identify the variables known to be important, and higher thresholds may include variables that are of questionable importance.[24]

Lastly, future research should examine the specific mechanisms of the interconnections within a dyad, composed of the HCW and the patient and/or the main familial or institutional caregiver. Actor–partner interdependence models may determine how parameters among each member of the dyad are influenced, not only by internal factors but also by factors related to the other member of the dyad.

CONCLUSION

This research provides preliminary evidence that caring for patients with severe and complex disabilities has a negative and positive impact on the QoL of an HCW. The results support the need for progress in specialized centres to optimize adaptation of the work environments for HCWs caring for such dependent patients, the need to maintain a high staff/patient ratio around these specific patients, and the need to implement targeted actions to support HCWs.

ACKNOWLEDGEMENTS

This work was financially supported by French PREPS (Programme de recherche sur la performance du système de soins, year 2013) and the French Institute National de la Santé et de la Recherche Médicale (INSERM, year 2013): Grant DGOS and INSERM. The sponsor was represented by Assistance Publique, Hôpitaux de Marseille, France, and its role was to control the appropriateness of the ethical and legal considerations. We are grateful to all the HCWs for their participation in the study, and

to Latif Abdallah Aden and Daniel Willocq for their logistical support. The authors have stated that they had no interests which might be perceived as posing a conflict or bias.

SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Details and references for the psycho-behavioural data.

Table SI: Sociodemographic and professional characteristics of health care workers.

Table SII: Relationships between quality of life scores and characteristics of the health care workers (univariate analysis).

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RESUMEN

IMPACTO DE CUIDAR DE PACIENTES COM DEFICIÊNCIAS GRAVES E COMPLEXAS NA QUALIDADE DE VIDA DE PROFISSIONAIS DA SAÚDE: DETERMINANTES E ESPECIFICIDADES

OBJETIVO Las personas con discapacidades severas y complejas, definidas por una combinación de deficiencia intelectual y déficit motriz grave que resulta en una extrema dependencia, a menudo permanecen en el hospital o en centros de atención residencial. El objetivo de este estudio fue identificar determinantes de la calidad de vida de 238 trabajadores de la salud que cuidan a individuos con discapacidades severas y complejas.
MÉTODO Se realizó un estudio transversal. El reclutamiento de los trabajadores de la salud se realizó en cinco centros franceses especializados en pacientes con discapacidades severas y complejas. Los criterios de selección fueron: mayores de 18 años, ser un trabajador de la salud actuando como referente institucional (un referente que coordina varias actividades para o sobre el paciente), y aceptar participar. Se colecto las siguientes variables: características socio demográficas, estado de salud, variables profesionales y psico-conductuales (calidad de vida, nivel de agotamiento [burnout], y las estrategias para afrontar el estrés [coping]).
RESULTADOS De los 362 trabajadores de la salud elegibles para el estudio, el 65,7% devolvió los cuestionarios. Las puntuaciones de las áreas físicas y sociales de la calidad de vida de los trabajadores de la salud fueron significativamente menores, y la puntuación psicológica significativamente mayor, que las de un grupo de comparación. Los factores principales que modulan la calidad de vida de los trabajadores de la salud fueron: la edad, las dificultades financieras, la naturaleza de la estrategia de afrontamiento del estrés y el nivel de agotamiento.
INTERPRETACIÓN Este estudio proporciona evidencia preliminar de que el cuidado de pacientes con discapacidades severas y complejas afecta la calidad de vida de los trabajadores de la salud. Estos resultados respaldan la optimización de los entornos de trabajo para los trabajadores de la salud.

RESUMO

IMPACTO DE CUIDAR DE PACIENTES COM DEFICIÊNCIAS GRAVES E COMPLEXAS NA QUALIDADE DE VIDA DE PROFISSIONAIS DA SAÚDE: DETERMINANTES E ESPECIFICIDADES

OBJETIVO Indivíduos com deficiências graves e complexas, definidas como a combinação entre deficiência intelectual profunda e déficit motor grave, resultando em dependência extrema, geralmente permanecem em hospitais ou em residências institucionais. A meta deste estudo foi identificar os determinantes de qualidade de vida *(QoL*) de 238 trabalhadores da saúde (*HCWs*) envolvidos no cuidado de pessoas com deficiências graves e complexas.
MÉTODO Foi conduzido um estudo transversal. Os *HCWs* foram recrutados em cinco centros franceses especializados em pacientes com deficiências graves e complexas. Os critérios de inclusão foram idade acima de 18 anos, ser um *HCW* de referência institucional (ser uma pessoa de referência para a coordenação de assuntos diversos relacionados ao paciente) e a concordância em participar. Variáveis sócio-demográficas, de saúde, variáveis profissionais e dados psico-comportamentais (*QoL*, esgotamento-*burnout*-e estratégias de enfrentamento–*coping*) foram registradas.
RESULTADOS Dos 362 *HCWs* elegíveis, 65,7% retornaram os questionários preenchidos. As pontuações obtidas para as dimensões física e social do *QoL* foram significantemente inferiores e a pontuação da dimensão psicológica foi significantemente superior, comparadas a um grupo controle. Os fatores principais na modulação da qualidade de vida foram a idade, dificuldades financeiras, natureza da estratégia de enfrentamento e presença de esgotamento.
INTERPRETAÇÃO Esta pesquisa fornece evidência preliminar que o cuidado de pacientes com deficiências graves e complexas, afeta a qualidade de vida de trabalhadores da saúde. Estes resultados apoiam a necessidade de melhorias no ambiente de trabalho de profissionais de saúde.