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► To cite this version:

M.-C. Rousseau, K. Baumstarck, P. Auquier, T. Billette de Villemeur. Health characteristics and health care trajectory of polyhandicaped person before and after 1990. *Revue Neurologique*, 2020, 176 (1-2), pp.92-99. 10.1016/j.neurol.2019.04.009 . hal-03252356

HAL Id: hal-03252356

<https://hal.science/hal-03252356>

Submitted on 7 Mar 2022

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HEALTH CHARACTERISTICS AND HEALTH CARE TRAJECTORY OF POLYHANDICAPED PERSON BEFORE AND AFTER 1990¹

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¹ **Authors' contributions** : Conception and design: MCR, TBV, PA. Study coordination: MCR, TBV, KB, PA. Acquisition of data: MCR, TBV. Analysis of data: MCR, KB. Interpretation of data: MCR, TBV, KB, PA. Drafting and writing of manuscript: MCR, KB. Revision and approval of final version of the manuscript: MCR, TVB, KB, PA.

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Abstract:

Introduction. Polyhandicap is defined as the combination of severe mental impairment and severe motor deficit resulting in reduced mobility and an extreme reduction in autonomy. Over the last 20 years, care management for these patients has become more structured, however, their care pathway is not always optimal. Objective: to describe/compare the health characteristics, treatment and history of the care pathways of subjects who received care before and after 1990.

Method. Multicentre cross-sectional study, population studied: patients with polyhandicap: i) causal brain damage < 3 years, ii) severe mental impairment, iii) motor disability iv) reduced mobility v) extreme restriction of autonomy. Data collected: clinical and medical, care procedures, treatments, history of care pathways.

Results. Patients are divided into 2 groups: 545 patients who received care after 1990 and 330 before 1990. Older patients present more recurrent urinary infections, slow transit, behavioural disorders and pain, and are prescribed a greater number of drugs. For those who received care before 1990, the age of admission to an establishment is lower, with one-third receiving a consultation dedicated to the transition from paediatric to adult teams.

Discussion/Conclusion. The care sector for patients with polyhandicap makes it possible to meet their needs throughout their lives, however, there is still progress to be made in terms of formalisation and of coordinating the care pathway in order to facilitate the transition from paediatric to adult services/establishments.

Key words: polyhandicap, health care pathway, care modalities, health status

Introduction:

Polyhandicap (PLH) is a French notion corresponding to a chronic affliction occurring in an immature brain, leading to a combination of a profound mental retardation and a serious motor deficit, and resulting to an extreme restriction of autonomy and communication [1]. This definition was adopted by the French scientific community and the French law (French Law n°89-798, 1989, October 27th, health policy of care disability). This term is close to the notion of Profound Intellectual and Multiple Disabilities, which is used in other countries, that does not systematically refer to a disorder affecting an immature brain [2]. Polyhandicap is a syndromic entity and meets several progressive and non-progressive etiologies.

It concerns a disorder, abnormality or lesion occurring in a developing or immature brain. Neurological, intellectual and motor disabilities are frequently accompanied by sensory deficits and behavioural and relational disorders. The prevalence of polyhandicap in France, estimated to be between 0.7 and 1.28 per thousand, i.e. 880 new cases of children with polyhandicap per year, is stable or even slightly increasing [3–5]. Today, the life expectancy of these patients often exceeds forty years and tends to be increasing further (Rousseau, unpublished data) [5–9].

The chronic nature of the health status of people with polyhandicap entails care management that not only provides the specific medical care required (treatment of episodes of decompensation and of comorbidities, measures to prevent the degradation linked to ageing), but also takes into account the social and educational dimension, in order to offer them a coherent, appropriate and integrative life plan. In France. The current structure of the health system allows patients with polyhandicap to benefit from different modalities of care: specialized re-education center providing high-level of medical care for patients presenting with the most severe health status, residential facilities offering more educational care for less severe individuals and home care corresponding to patients (adults and children) living at their parents' home, constituting a complex network. Given the evolving nature of polyhandicap over the course of the patient's life, care management must take into account changes in medical and educational characteristics [10,11].

Over the last 20 years, care management for patients with polyhandicap has become more structured: the provision of care has expanded with the creation of new facilities, in particular for childcare, and better support for families promoting care for children with a

disability in the family home. Despite these developments, however, the care pathway of patients with polyhandicap is not always optimal and can lack fluidity [12, 13]. This can result in interruptions in the provision of care, placing the burden of the latter on families. Furthermore, the improvement of knowledge with regard to the health characteristics and history of care pathways of patients with polyhandicap according to age may make it possible to identify avenues for optimisation.

The objective of this study is to describe and compare the characteristics of patients with polyhandicap, the treatment methods implemented and the history of care pathways among subjects who received care between 1990 and 2012 corresponding to subjects between the ages of 3 and 25, and among subjects who received care before 1990 corresponding to subjects over the age of 25. The objective of this study is to describe and compare the characteristics of patients with polyhandicap, the treatment methods implemented and the history of care pathways among subjects who received care between 1990 and 2012 corresponding to subjects between the ages of 3 and 25, and among subjects who received care before 1990 corresponding to subjects over the age of 25.

Method:

This is a multicentre cross-sectional study carried out using data from the Eval-PLH study in which 875 patients with polyhandicap were included between March 2015 and September 2016.

The patients included in this study were recruited from health and medicosocial establishments, in addition to certain subjects managed at home:

- 1) Patients within the health sector were recruited from 4 specialised re-education centres in France (3 centres of the Assistance Publique Hôpitaux de Paris (Paris University Hospital Trust – *APHP*): San Salvadour Hospital, La Roche Guyon Hospital and Hendaye Hospital and 1 centre of the *Union Générale des Caisses d'Assurance Maladies d'Ile de France* (General Union of Medical Insurance Services of Ile de France)), making it possible to represent more than 60% of patients with polyhandicap in specialized re-education centres nationally.
- 2) Patients within the medico social sector (residential facilities for children and for adult patients) were recruited from 9 of 17 centres of the *Comité d'Etudes, d'Education et de Soins Auprès des Personnes Polyhandicapées* (Research, Education

and Care Committee for Persons with Multiple Disabilities – *CESAP*) comprising 730 beds (250 for adults and 480 for children).

3) The consultation conducted at Trousseau Hospital (APHP) made it possible to study patients managed in their family homes in Ile de France.

▪ **Patient Inclusion Criteria**

We included all patients (incident and prevalent cases) seen in consultation or managed in participating centres and meeting all of the following inclusion criteria:

- Patient aged at least 3,¹
- Patient presenting a polyhandicap defined by the combination of the following 5 criteria:²
 - Causal brain damage or lesion occurring before the age of 3,
 - Intellectual Quotient under 40 or non-evaluable,
 - Motor disability: para/tetraparesis, hemiparesis, ataxia, neuromuscular disorders and/or extrapyramidal motor disorders,
 - Gross Motor Function Classification Level of III, IV or V [14],
 - Functional Independence Measure under 55 [15].

▪ **Data Collected**

- Sociodemographic data: gender, type of care at baseline (specialized re-education centres, residential facility or home care), type of service at baseline (adult or paediatric), aetiology of polyhandicap (known/unknown)
- Concept of severity of polyhandicap defined by the combination of the following criteria: motor disability (paraparesis or tetraparesis and/or extrapyramidal syndrome and/or severe general hypotonia), IQ < 25, FIM ≤ 20 and GMFCS IV and V
- Concept of instability of polyhandicap defined by at least one of the following criteria: recurrent pulmonary infections (≥ 5 per year), pharmaco-resistant epilepsy (≥ 4 seizures per month)

¹ Given that cases of children under the age of 3 are highly specific, it was agreed not to include them. The neurodevelopmental examination of very young children evolves from month to month, with great variability from one child to another. In addition, very young children cannot be assessed using a large proportion of the tests used in this study, particularly with regard to the evaluation of autonomy, communication, and cognitive and motor functions.

² The 5 criteria determining the presence of multiple disabilities were the subject of discussions between two experts, who are partners in the study, and the associated investigators in order to obtain a consensual definition, given the specificity of the concept in our organisation.

- Main comorbidities: orthopaedic, urinary, pressure ulcers, digestive (gastroesophageal reflux disease, swallowing disorders, slow transit)
- Presence of behavioural disorders (agitation, unexplained crying, merycism, bruxism, self-injury, aggressive behaviour, motor stereotypies, autistic withdrawal)
- Hetero-evaluated pain: *Echelle Douleur Enfant San Salvador* (San Salvador Children's Pain Scale – EDESS) (16)
- Sensory impairment: visual impairment, hearing impairment
- Treatments and care management:
 - Main treatment categories and number of drugs prescribed, in addition to the wearing of medical devices (gastrostomy, tracheotomy, respirator, urinary catheter, hetero intermittent urinary tests)
 - Rehabilitation care (number of physio, occupational and psychomotor therapy sessions per month), number of educational therapy sessions per month
- Patient development: the stage of cognitive development was evaluated using the Brunet-Lézine scale (17), which is a tool for evaluating the developmental quotient of children aged 0 to 2, making it possible to assess different neuromotor schemes and calculate a valid developmental quotient in children aged 1 month to 2 years. This developmental quotient cannot be used in patients over the age of 2, however, we decided to use the scale to assess the level of development of patients in each of the following 4 areas: posture, coordination, language and sociability, thereby obtaining a competency profile specific to each patient with multiple disabilities in each of these 4 areas.
- Data relating to the patient care pathway and its history
- History of patient care procedures: specialized re-education centre, residential facility (adult or paediatric unit), home care, etc., patient age on first and second admission to an establishment, patient age on first admission to an adult establishment or department
- Existence of a request to change care procedure (patient registration on a waiting list for a (different) care structure)
- Existence of formal procedures for the transition from child to adult care (studied for patients aged over 15 years)
- Speciality of the patient's current referring doctor
- Adequacy of care in relation to age: defined by an individual under the age of 18 treated in a paediatric unit or an individual over the age of 18 treated in an adult unit

- Cumulative duration of interruptions in care pathways, defined as a hiatus between 2 care procedures within establishments. Interruptions in the provision of care were studied across all 875 patients.

- **Statistics**

The group of subjects who received care between 1990 and 2012 have been compared with the group of subjects who received care before 1990. Qualitative variables are presented in terms of number and proportion for the 2 groups. Quantitative variables are presented in terms of mean, standard deviation, median, and 25th and 75th percentiles. Depending on the distribution of the variable, Chi² or Fisher's exact tests are used for qualitative variables. Comparisons between the 2 groups are made using the usual tests (Student's t-test, ANOVA) and non-parametric tests (Mann-Whitney, Kruskal-Wallis) according to the applicability of these different tests.

- **Ethics**

This study was approved by the *Comité de Protection des Personnes Sud Méditerranée V* (South Mediterranean V Ethics Committee), 20/10/2014, reference: 2014-A00953-44. Written consent was obtained from the legal representatives of each patient included in the study. Clinical trial number: NCT02400528.

Results:

The eight hundred and seventy-five patients with polyhandicap aged 3 to 68 included in our study are divided into 2 groups: 545 patients who received care between 1990 and 2012 (subjects aged between 3 and 25) and 330 patients who received care before 1990, corresponding to subjects aged over 25 (subjects aged 26 to 68).

For the 2 patient groups, there is a slight majority of men/boys (53%). Among the subjects who received care before 1990 (older group), the aetiology of polyhandicap remains unknown more often (17%) than among the subjects (12%) who received care after 1990 (younger group).

- **Clinical Characteristics at Baseline :**

Almost all the patients who received care before 1990 (older group) are actually managed in an establishment (specialized re-education centre or residential facility) and present

polyhandicap that is more severe but less unstable in comparison with the subjects who received care after 1990 (younger group). The frequency of comorbidities varies according to period of life, with patients who received care before 1990 (older group) presenting more recurrent urinary infections, slow transit, behavioural disorders and pain. Certain comorbidities, such as hip dislocations and pressure ulcers, do not vary between the 2 groups. Among the subjects who received care after 1990, there is a higher proportion of visual impairment, whereas the proportion of hearing impairment is similar for the 2 groups. The number of drugs prescribed and the proportion of laxatives, analgesics and psychotropics increases significantly among the subjects who received care before 1990, whereas the wearing of medical devices is more frequent among the subjects who received care after 1990. Regarding paramedical care: the number of physiotherapy sessions per month remains unchanged, irrespective of the patient group; conversely, the number of psychomotor and occupational therapy sessions and educational therapy decreases among the older group (patients who received care before 1990). The neurodevelopmental level of the young subjects is higher than that of the older group (patients who received care before 1990). The results corresponding to the medical characteristics of the two groups of patients with polyhandicap are presented in Table 1.

- Care Management from Birth:

The care pathways vary according to age: for the older patient group, the age of their first admission to an establishment is earlier (15 months, compared with 2 years for the younger patients). The transition from child to adult care was studied for patients aged over 15. One-third of the older subjects received a consultation dedicated to the transition from paediatric to adult teams.

For all 875 patients, the adequacy of care management in relation to age shows that 10% of adults are received in the paediatric sector, and the cumulative median duration of interruptions in the provision of care for all patients is 31 months (IQR) [10-66].

Twenty-one percent of the young subjects (3-25 years) are awaiting referral or transfer to another establishment.

The median age of admission to an adult establishment or department (19 years) is similar for the 2 groups.

The speciality of the referring doctor for the care management of the patient varies greatly with age: 47% of the subjects of the younger group are managed by a paediatrician or

paediatric neurologist, 16% by a rehabilitation physiotherapist, and 35% by a GP; whereas the subjects of the older group are managed by a GP in over 80% of cases. The detailed results corresponding to the care pathways of the two groups of patients with polyhandicap are presented in Table 2.

Discussion:

This study makes it possible, for the first time in France, to describe the health characteristics and care procedures in a large population of subjects with polyhandicap, in addition to the details of their care pathways over the last few decades.

1) The first finding is that the clinical characteristics of patients who received care before 1990 (26-68 yrs) and after 1990 (3-25 yrs) differs significantly. The distribution of comorbidities shows that there is a high risk associated with the advancement of age in patients with polyhandicap: the first period of life of patients with polyhandicap is characterised by a greater instability of polyhandicap related to epilepsy and respiratory complications. Indeed, in childhood, epilepsy, often pharmaco-resistant, related to progressive diseases is the main factor contributing to the instability of polyhandicap and premature death (10).

We also note that, among the young subjects, aetiological diagnoses are more precise and better documented, because they have benefited from advances in genetics and imaging in this field (18).

Adolescence is marked by the worsening of spasticity which, combined with growth, leads to a sharp increase in scoliosis, in turn increasing episodes of iterative pulmonary infections resulting from a combination of different factors (scoliosis with thoracic deformation, swallowing disorders, gastroesophageal reflux disease, insufficient bronchial drainage measures, transit disorders, etc.), which contribute to the unavoidable degradation of the respiratory function, the main cause of death among these patients [9]. Fortunately, advances in spasticity management and rehabilitation (moulded corset-seats, night foam, antispastic treatments, botulinum toxin) and early treatment of scoliosis from early adolescence (arthrodesis) have significantly changed the life-threatening prognosis and quality of life of these patients, with a greater number surviving through to adulthood [16-19].

Patients in the older group of subjects present a more severe polyhandicap, in line with increased dependence. Ageing in people with polyhandicap is significantly marked by an increase in motor disability and cognitive impairment, resulting in a greater severity of polyhandicap. A certain number of comorbidities are more frequent in the older subjects: transit disorders and urinary infectious episodes increase with age, and behavioural disorders present in 85% of patients over the age of 25 are often the reason for their admission to an establishment. On the contrary, the higher proportion of visual impairment in subjects who received care after 1990 likely indicates progress in the diagnosis of ophthalmological disorders among such non-communicative patients.

Patients with polyhandicap are at high risk of pain and discomfort related to spasticity, joint deformities, areas supporting the body, invasive procedures, etc.: 10% of children and young adults suffer from pain, with this figure rising to 32% among subjects over the age of 25. However, this proportion is lower than in patients with cerebral palsy and is likely to be underestimated, because pain in patients with polyhandicap is underdiagnosed due to their reduced capacity for communication [20–22]. It is known that patients with polyhandicap are less often subject to skin complications (pressure ulcers and areas supporting the body) compared with patients with other conditions confining them to a bed, such as multiple sclerosis or tetraplegia [23-25], and the prevalence of pressure ulcers is very low (approximately 5%) irrespective of age. We can infer that subjects with polyhandicap who have grown up bedridden have a higher tolerance in areas supporting the body and are less susceptible to skin complications compared with subjects with acquired disability.

In fact, the comparison between older and young subjects has to be cautious and must take into account that the care of PLH patients has improved in the last 20 years.

The mean number of drugs prescribed to people with polyhandicap is significantly higher for the older subjects. The proportion of laxatives, analgesics and psychotropics correlates with the increase in the associated comorbidities with age. Nearly half of the children and young adults carry medical devices (gastrostomy, tracheotomy, etc.) in line with neuro-orthopaedic and respiratory problems. This proportion subsequently decreases, because these weaker patients generally die before the age of 50 from respiratory complications [10]. Our study shows that, regrettably, people with polyhandicap do not receive intensive rehabilitation and educational care. Children with polyhandicap frequently present muscle tone disorders resulting in the delayed or impossible acquisition of movements, which hinders the

development of somatognosia and spatiotemporal references. Furthermore, their cognitive development scarcely reaches a level equivalent to 5 to 7 months of normal development, both in the motor (posture, coordination) and cognitive (language, socialisation) fields. Beyond the age of 25, this level, which is already very low, does not increase and tends to decrease in the older group of patients, owing to a lack of sensorimotor experience and of educational therapy, which is often insufficient in institutions. Indeed, the care teams supporting these patients cite the lack of educational staff in establishments caring for people with polyhandicap, and the educational teams feel unequipped to care for those individuals who present a very low level of neurodevelopment.

Similarly, the majority of specialised paramedical care (psychomotor therapy, occupational therapy) decreases for subjects cared managed before 1990, and the number of physiotherapy sessions is low (8 per month), whereas orthopaedic prevention remains necessary in adults in order to limit the consequences of spasticity and confinement to a bed.

1) Secondly, this study has the benefit of producing, for the first time, data relating to the care pathway of people with polyhandicap, which has evolved over the last 25 years: we have found that the age of first admission to an establishment is now higher, because parents keep their child at home for longer, with less recourse to specialized reeducation centres as a consequence. Two factors can explain this: the development of our society in favour of less stigmatisation and greater inclusion in respect of disability, and also the improvement in support for carers and home care conditions vis-à-vis children with polyhandicap. The age of recourse to care in an adult establishment has not changed in the last 25 years, however, the cumulative duration of interruptions in the provision of care during intervening periods between two establishments is significant (2 and a half years), placing the burden on families. The transition from child to adult care remains underprepared. Paediatric care is dense, multidisciplinary and specialised, whereas adult care is less defined, sometimes leaving families feeling abandoned. Another fact worth noting is that the majority of patients who receive care at home are children or young adults, whereas, beyond the age of 25, virtually all patients receive care in establishments. It may be inferred that families likely manage to keep their children at home during early years, even those with polyhandicap and a very high level of dependency. Subsequently, as parents become older, it no longer remains possible for them to provide the relevant care,

leading them to request that their child be placed in an establishment. The majority of older subjects, who have more severe polyhandicap, therefore requiring care management in a medical setting, receive care in a specialised re-education centre.

The adequacy of care management in relation to the age of the patient shows that 10% of adults are in a paediatric establishment, which correlates with the results of a survey conducted by the *Direction de la Recherche, des Etudes, de l'Evaluation et des Statistiques* (Directorate for Research, Studies, Evaluation and Statistics – *DREES*) that estimated the proportion of adults with a disability managed in paediatric establishments at 13% and a high mean age of admission to adult establishments [26]. Several explanations can be put forward: a lack of places in adult establishments (one-fifth of those under 25 are awaiting transfer to another establishment), as well as a significant lack of geographical coverage, particularly as regards the provision of medical care (specialised re-education centres). However, there are other obstacles to the transition from child to adult care, relating to a reluctance on the part of care staff and parents, who have often built up strong emotional ties over time, resulting in a therapeutic alliance centred around the care of the child. Both are aware that the paediatric care network is denser and offers more specialised establishments consisting of multidisciplinary teams, which further reinforces these reservations. Our study confirms this: the majority of doctors in charge of managing children and young adults are specialists (paediatricians, paediatric neurologists or rehabilitation physiotherapists), whereas older subjects are managed by a GP in 70% of cases. Therefore, there is progress to be made, on the one hand, to improve support with regard to the transition of patients with polyhandicap from paediatric to adult teams, which requires preparation from adolescence, and, on the other hand, it is necessary to improve care management for older patients by training more rehabilitation physiotherapists and paramedical staff specialised in the particularities of caring for ageing patients with polyhandicap, in order to provide a high quality of multidisciplinary care.

Conclusion:

All of these findings illustrate the complex needs of people with polyhandicap in terms of care, who, at every period of life, must have access to specific, complex and long-term care.

While the tripartite care management system for people with polyhandicap in France, spread between the specialized re-education centres, residential facilities and home care, makes it possible to meet all of the needs of a person with polyhandicap throughout their

lifetime, progress is still to be made in terms of formalisation, in order to provide greater clarity for families and professionals, and in terms of coordinating the care pathway in order to facilitate the transition from paediatric to adult services/establishments.

Acknowledgements:

This work is 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 funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Declarations of interest

The authors declare that they have no vested interests.

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Table 1 : Sociodemographics and health status of polyhandicapped patients of the 2 groups

Patients characteristics at baseline		3-25 years N= 545 N (%)	26-68 years N= 330 N (%)	p-value
General characteristics				
Gender		290 (53.2) H/255 (46.8) F	176 (53.3) H/154 (46.7) F	0.001
Unknown Etiology		63 (11.8)	56 (17)	0.03
Care modality/structure	Spec. Reeduc.center	198 (37)	212 (64.2)	<0.0001
	Residential facility	255 (47.6)	117 (35.5)	
	Home care	83 (15.5)	1 (0.3)	
Severity		262 (48.6)	227 (69.2)	<0.0001
unstability		180 (33.6)	35 (10.8)	<0.0001
Comorbidities				
Reccurent urinary tract infection ^a		37 (7)	42 (12.8)	0.004
Hip luxation		126 (24.6)	93 (29.2)	0.14
Scoliosis ^b		273 (52.1)	251 (48)	<0.0001
Epilepsy		311 (58.5)	167 (50.8)	0.02
Fecal impaction		201 (38.4)	212 (65.8)	<0.0001
Bedsore		28 (5.2)	15 (4.6)	0.67
Behavior disorders		339 (63.7)	283 (85.8)	<0.0001
Chronical pain		52 (9.6)	105 (32)	<0.0001
Visual impairment		165 (31)	80 (24.7)	0.04
Hearing impairment		33 (6.3)	17 (5.3)	0.53
Treatments and reeductive management				
Number of medications Moy±SD		6.5±3.4	8.2±3.4	<0.0001
Laxatives		345 (7.)	314 (97)	<0.0001
Antalgics		281 (52.2)	226 (69)	<0.0001
Psychotrops		151 (31.5)	241 (75)	<0.0001
Medical devices (at least one)^c		223 (41.4)	94 (28.7)	<0.0001
Physiotherapy sessions/month (Med (IQR))		8 [8-16]	8 [4-12]	0.15
Ergotherapy sessions/month Med [IQR]		0 [0-4]	0 [0-0]	<0.0001
Psychomotor sessions/month Med [IQR]		4 [0-4]	0 [0-0]	<0.0001
Educational sessions/month Med [IQR]		4 [0-12]	0 [0-8]	<0.0001
Neurodevelopmental status^d				
Neurodevelopmental status based on Brunet-Lezine scores/months ^d Med [IQR]	Posture-motor ability *	5 [2-9]	3 [2-5]	<0.0001
	Coordination*	5 [2-8]	3 [2-5]	<0.0001
	Language*	5 [2-9]	2 [2-4]	<0.0001
	Sociability *	6 [2-10]	3 [2-5]	<0.0001

^a At least once a year. ^b Scoliosis with thoracic deformation. ^c at least one of the following list: invasive mechanical ventilation, non-invasive mechanical ventilation tracheotomy, nasogastric tube, gastrostomy, permanent urinary probe, cerebrospinal fluid derivation, and central venous catheter

^d Neurodevelopmental status based on Brunet-Lezine scores (levels range from 0 to 24 months)

*Missing data > 15%, Med [IQR]

Med [IQR] median and interquartile range

Moy±SD mean ± standard deviation

Table 2 : Health care pathway of polyhandicapped patients of the 2 groups

Health care pathway		3-25 years N=545 N (%)	26-68 years N=330 N (%)	p-value
Patient age on first admission (months) Med [IQR] ^a		24 [6-54]	15 [0-60]	0.023
Patient age on second admission (months) Med [IQR] ^b		60 [44-96]	84 [40-165]	<0.0001
First care modality	Home care	307 (56.3)	91 (27.6)	
	Specialized reeducation centre	102 (18.8)	125 (38)	
	Paediatric residential facility	62 (11.4)	60 (18.1)	
	Adult residential facility	0 (0)	5 (1.5)	
Second care modality	Home care	98 (18)	6 (1.8)	
	Specialized reeducation centre	108 (19.8)	109 (33)	
	Paediatric residential facility	157 (28.8)	71 (21.5)	
	Adult residential facility	25/116 (4.6)	58/209 (17.6)	
Formal procedure for transition ^c		15 (13)	67 (32)	
Patient age on first admission in adult unit (months) Med [IQR]		19 [17-20]	19 [11-26]	0.07
Existence of a request to change care procedure		94 (20.8)	13 (4)	
Speciality of the patient's referring doctor	Paediatrician/paediatric neurologist	254 (47.4)	23 (7)	
	Rehabilitation physiotherapist	88 (16.4)	41 (12.4)	
	General practitioner	187 (35)	266 (80.6)	

^aPatient age on first admission to an establishment

^bPatient age on second admission to an establishment

^cStudied from the age of 15

Med [IQR] median and interquartile range

Moy±SD mean ± standard deviation