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POLYHANDICAP AND AGING

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Keywords

Polyhandicap; aging; health status; rehabilitation procedures; comorbidities; medications

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1 **Abstract**

2 **Background.** Knowledge of the health status and care management of elderly individuals with
3 polyhandicap (PLH) is lacking; however, a better understanding of the natural course of ageing in PLH
4 persons would help optimize preventive and curative care management strategies.

5 **Objectives.** To describe PLH persons aged 18 to 68 years by providing i) a description of their health
6 status and ii) a description of their medications, medical devices and rehabilitation procedures.

7 **Methods.** This was an 18-month cross-sectional study including people aged 18 to 68 years with a
8 combination of severe motor deficiency and profound intellectual impairment. They were recruited
9 from 4 specialized rehabilitation centres, 9 residential facilities, and a neurological department. The
10 following data were collected: polyhandicap aetiology, health status, medical devices, and
11 rehabilitation procedures.

12 **Results.** A total of 474 PLH persons were included (N=219 [18-34 years], N=151 [35-49 years], N=104
13 [50-68] years). The aetiology of polyhandicap was unknown for 13% to 17% of PLH persons across the
14 3 age classes. Behavioural disorders and pain were more frequent in the oldest age classes. Elderly
15 PLH persons had more severe but less unstable polyhandicap. Their neurodevelopmental was close
16 to that of a 4-month-old child without progression across age. Gastrostomy was the most frequent
17 device needed by the PLH persons.

18 **Conclusions.** The longevity of PLH persons is improving; some of these persons, among whom are the
19 least unstable and with less comorbidity, can survive for more than 50 years due to the improvement
20 of preventive actions and supportive care.

21

22 **Keywords**

23 Polyhandicap; ageing; health status; rehabilitation procedures; comorbidities; medications

24

1 **Introduction**

2 Polyhandicap (PLH), as a recently defined concept (1–3), is a dramatic health condition with severe
3 and complex disabilities corresponding to a chronic disorder occurring in an immature brain, leading
4 to a combination of profound intellectual impairment and a serious motor deficit and resulting in an
5 extreme restriction of autonomy and communication. Polyhandicap is close to the notion of
6 profound intellectual and multiple disabilities used in other countries that does not systematically
7 refer to a disorder affecting an immature brain (4). Polyhandicap is a syndromic entity and meets
8 several progressive and non-progressive aetiologies, and the scarce data available in France enable
9 an estimation of the prevalence of polyhandicap as between 0.7 and 1.3 per thousand (5). In
10 polyhandicap, heavy cerebral damage occurring on an immature brain explains the severe health
11 condition of the polyhandicaped persons, resulting in the entanglement of multiple handicaps and
12 comorbidities; this condition worsens with ageing and leads to premature death (2,6). The life
13 expectancy of polyhandicaped persons is partially and heterogeneously described in a literature that
14 varies considerably in the size of the population studied and in the design of the study. It may vary,
15 according to the data in the literature from 15 to 40 years old (6–8), which is lower than cerebral
16 palsy people who, depending on the seriousness of their condition, can reach a slightly reduced life
17 expectancy compared with the non-disabled population (9,10). In recent decades, a better
18 understanding of pathophysiology and the development of new care management strategies and
19 rehabilitation strategies adapted to these extreme pathologies has led to progress in the
20 management of children and adults. Although knowledge of health status and care management of
21 the oldest individuals is lacking, a better understanding of the natural course of life of PLH persons
22 would consequently allow optimizing the preventive and curative care management strategies (2).
23 This study aims to describe adult PLH persons aged 18 to 68 years and provide i) a description of their
24 health status (including severity, comorbidities and handicaps, neurodevelopmental status) and ii) a
25 description of their medications, medical devices and rehabilitation procedures. This description
26 considered 3 age classes: 18 to 34 (young adults), 35 to 49 (middle-aged adults), and 50 to 68 years
27 old (seniors).

28

29

1

2 **Methods**

3 **▪ Design and settings**

4 This study was a cross-sectional study including PLH persons from March 2015 to September 2016.

5 The recruitment of PLH persons was performed in 4 specialized rehabilitation centres, from 9
6 residential facilities, and from a specialized neurological department of a university hospital (UPMC,
7 Hôpital Trousseau, Assistance Publique Hôpitaux de Paris, France) during routine visits. This study
8 was included in the French national PoLyHandicap cohort.

9 **▪ General organization of the PLH cohort**

10 The French national PLH cohort was implemented in various French centres spread over different
11 territories: specialized rehabilitation centres, residential facilities, and a university hospital centre
12 (Paris, France). The general aim of the cohort was to identify the effect of socioeconomic,
13 environmental, and epidemiologic determinants on the health status of PLH persons and the daily
14 life of their natural and institutional caregivers (National Clinical Trial registration number
15 NCT02400528). Three different populations were eligible: i. People with severe polyhandicap; ii.
16 familial referents of the included PLH persons (French legal mention for this type of patient,
17 represented by parents in the majority of cases); and iii. Institutional health care workers of the
18 included PLH persons. The present study focused on adults.

19 **▪ Selection criteria**

20 The differences in terminology (polyhandicap, PIMD, etc.) have led us to use objective criteria
21 defined with scales recognized internationally for inclusion criteria. The patient selection criteria
22 were as follows: 18 to 68 years of age; a polyhandicap defined by the combination of motor
23 deficiency (tetraparesia, hemiparesis, paraparesia, extrapyramidal syndrome, cerebellar syndrome,
24 and/or neuromuscular problems), profound mental handicap (intelligence quotient (IQ) <40¹)
25 associated with everyday life dependence (Functional Independency Measure (FIM) <55), and
26 restricted mobility (Gross Motor Function Scale (GMFCS) III, IV and V); age at onset of cerebral lesion
27 below 3 years old.

28 **▪ Data collection**

29 Data were collected from medical records obtained by a dedicated clinical research assistant and
30 were supported by the referent physician of the patient (a referent physician is designated for each
31 patient). The data included the following items: sociodemographic data, known or unknown

¹For **PLH persons** older than 5 years old: IQ= developmental age below 2 years old; for children from 3 to 5 years old: IQ= developmental quotient<40%.

For **PLH persons** older than 5 years old IQ= developmental age below one year old, for children from 3 to 5 years old: IQ= developmental quotient<25%.

1 aetiology of the polyhandicap, health status, medications, medical devices and rehabilitation
2 procedures and adaptation of educative care.

3

4 1) Sociodemographic data: age category based on age at inclusion (3 age classes were defined: young
5 adults [18-34], middle-aged adults [35-49], seniors [50-68]), gender, and modality of care
6 management: the specialized rehabilitation centres offer a high level of medical and paramedical
7 care, the residential facilities offer a high level of psychosocial education and a lower level of medical
8 care, home care persons corresponds to PLH persons (adults and children) cared for at their parent's
9 home: they were recruited from a specialized neurological department of a university hospital during
10 a routine visit.

11 2) Aetiology status: classified as unknown or known.

12 3) Health status:

13 - Global health severity: i. severe for people with disabilities who meet all the following criteria:
14 motor impairment (paraparesia or tetraparesia and/or extrapyramidal syndrome and/or severe
15 general hypotonia), IQ <25, FIM ≤20, and GMFCS IV and V; ii. less severe for people with
16 disabilities who do not meet these criteria,

17 - Global health stability: i. unstable for people with disabilities who meet at least one of the
18 following criteria: recurrent pulmonary infections (>=5/yr) or drug-resistant epilepsy (>=4
19 seizures/month); ii. stable for people with disabilities who do not meet any of these criteria,

20 - Associated handicaps: i) severe motor impairments: tetraparesia, paraparesia, and hemiplegia; ii)
21 other neurologic impairments: movement disorders, severe dystonia, global hypotonia,
22 extrapyramidal syndrome, and ataxia; iii) neurosensory impairments: visual impairment
23 (partial/complete blindness) and hearing impairment (partial/complete deafness); iv)
24 behavioural disorders (including withdrawn behaviour (11)², intermittent screaming and crying,
25 agitation, self-aggressivity or hetero-aggressivity, stereotypies and/or merycism); and v) sleep
26 disturbance (short sleep, wake up at night, and difficulties falling asleep).

27 Comorbidities: epilepsy (yes/no; at least one previous onset of status epilepticus reported in the
28 medical file, drug-resistant epilepsy defined by more than 4 seizures per month despite adapted
29 anticonvulsant treatment, including at least 3 anticonvulsant drugs), orthopaedic (scoliosis, limb
30 deformations, limb fractures, hip luxation, neck stiffness, previous arthrodesis and/or other
31 previous orthopaedic surgery), pulmonary (pulmonary recurrent infections, aspiration syndrome,
32 chronic bronchial congestion), digestive (drooling, multiple caries, faecal impaction, gastro-
33 oesophageal reflux), urinary (recurrent urinary tract infections-at least once a year, urinal

² such as having a closed, sagging posture or making repelling gestures in response to activities that were offered.

1 retention, renal failure), cutaneous (bedsores, pressure sore), and pain evaluated with the pain
2 evaluation scale specifically developed for PLH persons with severe cerebral palsy (12), this scale
3 is based on modifications of the usual behaviour of the patient, referred to a personal “basic
4 chart” describing the usual state of the patient in different conditions.

- 5 - Chronic diseases (at least one of the following diseases: vascular stroke, myocardial infarction,
6 diabetes, and cancer).
- 7 - Neurodevelopmental patterns: General neurodevelopmental status was assessed using an
8 adapted version of the Brunet-Lézine scale. This scale was available for infants up to 24 months
9 old (13). In the present study, only the 4 developmental domains (language, posture-motor
10 abilities, coordination, and sociability) were used (13). All scores ranged from 0 to 24 months.
- 11 - General autonomy: Functional Independence Measure score (FIM).

12 4) Medications, medical devices and rehabilitation procedures management, physiotherapy sessions,
13 hygiene and going out:

- 14 - Medications: number of medications per patient and type of medication, including laxatives,
15 anticonvulsants, analgesics, psychotropics, antispasitics, antidystonics, antibiotics, osteoporosis
16 preventions, and martial supplementation.
- 17 - Medical devices: at least one versus none; number and type (invasive mechanical ventilation,
18 non-invasive mechanical ventilation, tracheotomy, gastrostomy, permanent urinary probe,
19 cerebrospinal fluid derivation, and central venous catheter).
- 20 - Rehabilitation procedures: sitting devices at least 3 hours/day, bed positioning in orthosis, limb
21 orthosis, verticalization device at least once a day, number of physiotherapy sessions per month,
22 number of patient transfers per day from bed to reeducation devices and from bed to shower
23 devices, hygiene through daily shower, going out at least once a day. Referent clinician’s feeling
24 about adaptation of educative care received by PLH persons.

26 ■ **Statistics**

27 Three age classes were constituted from age at inclusion: 18-34 y, 35-49 y, and 50-68 y.
28 Demographics, health status, and medical devices/rehabilitation parameters were described for each
29 age class. Trends over age classes were assessed (Jonckheere-Terpstra test, Cochran-Armitage, and
30 Kendall Tau test). Statistical analyses were performed using SPSS software (IBM SPSS PASW Statistics
31 Inc., Chicago, Ill USA). All tests were two-sided. The threshold for statistical significance was
32 established at $P < 0.05$.

33 ■ **Ethics approval and consent to participate**

1 Regulatory monitoring was performed according to the French law that requires the approval of the
2 French ethics committee (Comité de Protection des Personnes Sud Méditerranée V, 20/10/2014,
3 reference number 2014-A00953-44). A written consent form was obtained for each participant.
4 National Clinical Trials registration number NCT02400528. Registered 23 March 2015.
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Results

▪ **General characteristics of the sample**

During the 18-month study period, a total of 474 PLH persons aged 18 to 68 years (ratio included/eligible PLH persons was 90%) were included: 219 (46.2%) PLH persons from 18 to 34 years, 151 (31.8%) from 35 to 49 years, and 104 (22%) from 50 to 68 years. The PLH persons' sex ratio was stable across the age ranges from 1 to 1.21. The oldest PLH persons (i.e., 50-68 y) were predominantly care managed in specialized rehabilitation centres, no PLH persons over 35 y were care managed at home, and very few (2%) of the youngest adults were managed at home. All of the details are provided in Table 1.

▪ **Aetiology status**

Aetiologies of polyhandicap were unknown in 13 to 17% of the cases across the 3 age classes.

▪ **Health status:**

1) Severity and stability: More than half of the individuals were defined as severe according to our definition (described above), and older PLH persons were more severe. Eight to 20% of the individuals were defined as unstable across the 3 age classes, and younger PLH persons were more unstable. The Functional Independent Measure significantly decreased in older age classes.

2) Associated handicaps: Fifty-three to 83.7% of the PLH persons presented tetraplegia. For the oldest individuals (50-68 years), the proportion of paraplegia (16 to 40%) and of global hypotonia (15.7%) were lower compared with the younger age classes. Extrapyramidal symptoms (rigidity and/or dyskinesia) was reported for 24% of the youngest age class (18-39 years) and increased with ageing (34% for the oldest classes). Severe dystonia was significantly decreased in older subjects. Movement disorders and ataxia were reported at a similar proportion for the 3 age classes. Approximately 25% of PLH persons presented with visual impairment, and 4 to 7% presented with hearing impairment with no evident change over time. Behavioural disorders were less frequent in younger PLH persons (74.5%) compared with older individuals (more than 90% after 50 years old). The proportion of sleep disorders did not change across the ages.

3) Comorbidities: Epilepsy proportion significantly varied across the age classes, with a higher proportion in young adults and seniors (57% to 62%, respectively) and a lower proportion (43%) in middle-aged adults. Drug-resistant epilepsy was less frequent for the oldest individuals (6.8% for the [50-68 y] class) compared with 14% in the younger classes. The previous onset of status epilepticus significantly decreased with ageing. Although scoliosis and PLH persons with previous arthrodesis significantly decreased with ageing, the other orthopaedic comorbidities remained stable with ageing. Pulmonary comorbidities (recurrent pulmonary infections and aspiration syndrome) remained stable, but the proportion of PLH persons suffering chronic bronchial congestion decreased

1 with age. The proportion of gastro-oesophageal reflux and drooling decreased with age, whereas the
2 proportion of faecal impaction regularly increased with the age of the PLH persons. Recurrent urinary
3 tract infections and urinal retention remained stable across ages, although renal failure increased
4 with ageing. Cutaneous comorbidities (pressure fragility and bedsores) decreased with age. The
5 proportion of PLH persons with pain increased with age. All details are shown in Table 1.

6 4) Neurodevelopmental status:

7 The developmental level of PLH persons according to the Brunet-Lezine scale was very low (2 to 3
8 months) and significantly decreased with ageing for all domains. All details are shown in Table 2.

9

10 ▪ **Medical devices and rehabilitation procedures:**

11 The total number of medications significantly increased with age but did not reach significance. The
12 proportion of laxative, analgesics, psychotropics (neuroleptics, antidepressants and anxiolytics) was
13 significantly higher with ageing; in contrast, the proportions of antispastic, antidystonic, antibiotics
14 and osteoporosis preventatives decreased with age. Anticonvulsant drug proportions are higher than
15 epilepsy proportions: anticonvulsant drugs include those given for analgesic purposes.
16 Anticonvulsant and martial supplementation proportions were not different across the 3 age classes.

17 The proportion of PLH persons with at least one medical device decreased with age: 42% for the [18-
18 34 y] class and less than 30% for the 2 other age classes. Gastrostomy was the most frequent device
19 that PLH persons needed (21% in the older age class and up to 37% for the younger age class). Few
20 PLH persons required tracheotomy, and the proportion significantly decreased in the older age class.
21 Very few PLH persons required permanent urinary probe, central venous catheter, or cerebrospinal
22 fluid derivation.

23 Almost all the PLH persons used sitting device (wheelchair sitting and positioning devices such as
24 contoured seat intended to increase postural stability) for more than 3 hr/day, and 34 to 46% of
25 them benefited from bed positioning. The proportion of PLH persons with limb orthosis and
26 verticalization devices significantly decreased with ageing.

27 The number of physiotherapy sessions was significantly lower for older PLH persons. Almost all PLH
28 persons of all age classes received a daily shower. A low proportion of PLH persons (7 to 10%) had
29 daily outings.

30 The number of transfers from bed to rehabilitation devices/shower devices decreased in older
31 subjects. Educative care was significantly less adapted in older age classes. All details are shown in
32 Table 3.

Discussion

Over the past two decades, early detection and management of handicaps and comorbidities have improved the disease course of PLH persons, consequently ageing is an emerging phenomenon and there is a need for research about ageing outcomes in this population. Although it is well documented in the literature that the most common predictors of early death in disabled people are the severity of motor and intellectual deficits (14), several studies for close pathologic conditions, such as persons with intellectual disability or cerebral palsy, have reported a continuing increasing life expectancy (15,16). Polyhandicap is a much heavier health condition; however, more PLH persons reach the forties, and in recent years, an increasing proportion of PLH persons have passed the age of 50. The global severity of polyhandicap increases with ageing due to both the increase of neurologic impairment (e.g., paraplegia, extrapyramidal syndrome) and the decrease of autonomy in link with the various comorbidities. Over 35 years of age, all PLH persons were institutionalized due to the ageing of their parents not allowing them to keep their children at home anymore, and the increasing severity of PLH in senior requires a higher level of medical and paramedical care; therefore, a growing proportion (up to 77% of seniors) was cared for in specialized rehabilitation centres offering predominantly medical care.

Our results show that young adults presented more unstable polyhandicaps with a higher proportion of the various comorbidities (tetraplegia, scoliosis, bronchial congestion, drooling, gastro-oesophageal reflux, drug resistant epilepsy, cutaneous comorbidities) and instability (pulmonary infections and drug-resistant epilepsy). Previous studies showed that these heavily affected PLH persons often die prematurely (before their forties) (6,7): in fact, in our study, the oldest PLH person group was half the size as the young adult group.

Ageing in PLH persons does not have the same characteristics of normal persons with a very low proportion of chronic diseases, partially explained by the relative young age of the individuals (lower than 70) and, similar to persons with intellectual disability, the absence of exposure to some cardiovascular and cancer risk factors (tobacco and alcohol) (17). Another surprising fact was the high proportion (90%) of behaviour disorders presented by the oldest PLH persons, the most frequent being withdrawn behaviour, intermittent screaming/crying, agitation and self-aggressivity.

Orthopaedic comorbidity prevention and care has improved over these decades, with specific attention given to the early treatment of spasticity, appropriate physiotherapy and positioning of PLH persons in adapted sitting devices and limb orthosis. Nearly all PLH persons in our study benefited from daily sitting positioning, and more than 40% benefited from bed positioning. This may explain why hip luxation, limb deformations and cervical stiffness remain stable through ageing, therefore, these findings highlight the importance to promote rehabilitation programs for persons with polyhandicap to help preventing long-term orthopedic complications.

Scoliosis with important curvature is a threatening comorbidity leading to chronic bronchial congestion and subsequent bronchial infections, and eventually to respiratory failure. In severe cerebral palsy, it has been shown that scoliosis progresses with age (18); inversely, in PLH persons, scoliosis frequency decreases with ageing. Two hypotheses may account for this finding: first, some of these PLH persons with important kyphoscoliosis suffer from respiratory failure in early adulthood inducing their premature death (6,19), and second, the prevention of scoliosis with early arthrodesis (at the beginning of adolescence) and the generalization of the use of sitting devices for appropriate postural support help prevent their aggravation. The reduced proportion of high curvature scoliosis in older PLH persons also partly explained the reduced proportion of gastro-oesophageal reflux with ageing.

It is surprising that only 14 to 40% of PLH persons received osteoporotic prevention because osteoporosis is related to the bedridden state and use of certain anticonvulsant drugs. Despite the decreased osteoporotic prevention in older PLH persons, non-traumatic limb fracture remains stable through ageing. It is therefore important to promote preventive aspects to the health professionals and to suggest osteoporosis prevention in these individuals with associated risk factors for this condition.

An increasing proportion of PLH persons suffered from pain with advancing age (more than 60% in older age class), and at the same time, 80% received analgesic medication; pain is common in PLH persons and related to spasticity inducing musculoskeletal deformities and joint dislocation, as well as to chronic constipation, gastro-oesophageal reflux and chronic bronchial congestion (20). This proportion is lower than in cerebral palsy people but probably underestimated due to the very limited communication abilities of PLH persons (21). Expectedly, sensory (visual and hearing) deficiencies remained stable throughout ageing because these deficiencies directly result from the aetiology of polyhandicap. Nevertheless, the proportion of PLH persons presenting visual impairment was lower than in other studies performed on children with intellectual disability and motor impairment (22,23), which can be explained by an under/misdiagnosis due to the very little communication ability of PLH persons. This emphasizes the need for systematic detection and diagnosis of sensory deficiencies to improve the well-being of PLH persons.

Concerning the neurodevelopmental aspects, our sample of adult PLH persons hardly reached the level of development equivalent to 2 to 3 months of normal development, both in motor (posture, coordination) and cognitive domains (language, socialization), and the developmental process no longer evolved during adulthood. Clinicians reported that educative care was adapted for 76% of young adults, but in senior PLH persons, this proportion was only 27%, which may have contributed

to worsening motor and cognitive deficits in the older subjects, while intensive and individualized educative care could help cognition (24,25). Despite a strained economic health system, it should be necessary to develop appropriate psychoeducational care that this population deserves.

Polyhandicaped persons, similar to cerebral palsy people, received polypharmacy with a mean of 8 medications per patient. The proportion per age class of the different categories of treatments evolved in parallel with the various comorbidities: the proportion of laxatives, analgesic and psychotropic drugs increased with age as the proportion of anticonvulsant drugs remained stable. Similar to cerebral palsy, the most frequently prescribed pharmacological treatments were analgesics, anticonvulsants, psychotropics and laxatives; inversely, antibiotic prescriptions are lower in PLH persons (10%) compared to CP persons (26). We hypothesize that PLH persons mainly cared for in institutions may benefit of health policies relatives to antibiotics use. The number of PLH persons receiving medical devices decreased with age, and the most common medical device was gastrostomy (30%). This high proportion was related to 20% of PLH persons with swallowing disorders, as it helps to prevent recurrent pulmonary infections and gastro-oesophageal reflux and maintaining good nutritional status (27). PLH persons at risk of aspiration were offered gastrostomy much sooner in their lives, helping them to maintain a better nutritional status; therefore, this may improve survival (28).

It was disappointing to learn that older subjects received less reeducation care than younger subjects with less physiotherapy and verticalization sessions, less orthetic procedures, less antispastic medications, and less orthopaedic surgery; they are also significantly less transferred from bed to seating devices than younger subjects. In fact, these PLH persons need regular rehabilitation care providing mobilization and positioning to control joint stiffness, thus facilitating installation, hygiene and comfort procedures and reducing pain and subsequent behavioural disorders and these elements should be taken in account by health-promotion programs to optimize the rehabilitation care of older PLH persons. This confirmed the observation that in adults and even more in the elderly, the medical and paramedical network is less dense and less multidisciplinary than for children, whereas with age, the severity of the polyhandicap increases and the need for medical and specialized paramedical care remain important: service and health care providers should be aware of the lifelong need of regular reeducation care for PLH persons

Strengths and limitations

Our study provided health characteristics across ages from a large and homogeneous population of PLH adults and seniors, as previous studies focusing on this population of PLH persons are smaller with nonhomogeneous samples. The results of this cross-sectional study must be considered with

caution and should be confirmed by future studies using longitudinal designs. The division of our population of adults into 3 age classes from young to older adults was arbitrary and aimed to form 3 age classes of approximately 15 years: young, middle-aged adults and seniors.

Conclusion

In recent years, we have observed that the longevity of PLH persons is improving; some of these PLH persons, who are among the least unstable and with less comorbidity, can survive for more than 50 years, and this is due to the improvement of preventive actions and supportive care. The aging of polyhandicaped persons presents some characteristics (behavioral disorders, chronic constipation, and pain) which must be the subject of specific prevention and care to improve their well-being and to reduce the acquiring of additional medical conditions. These elements should be taken into account by clinicians, caregivers and health-decision-making authorities.

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Table 1. Sociodemographics and health status of polyhandicaped persons (N=474)

		18-34 years	35-49 years	50-68 years	p	trends	MD	
		N=219	N=151	N=104			%	
		N (%)	N (%)	N (%)				
1) Sociodemographics								
Sex ratio	Men/women	1.2	1	1.4	0.65	=	0	
Care modality/structure	Spec. Reeduc.center	92 (42)	104 (69)	81 (77.8)	<10 ⁻³	↗	0	
	Residential facility	122 (55.7)	47 (31)	23 (22.2)				↘
	Home care	5 (2.3)	0 (0)	0 (0)				↘
2) Etiology	Unknown	37 (17)	25 (16.6)	14 (13.5)	0.44	=	0.4	
	Known	180 (83)	126 (83.4)	90 (86.5)				
3) Health status								
Severity	Less severe	100 (46)	49 (32.7)	26 (25)	<10 ⁻³	↗	0.4	
	Severe	118 (54)	101 (67.3)	78 (75)				
Stability	Stable	171 (80)	130 (87.8)	93 (91.2)	0.005	↘	2.1	
	Unstable	43 (20)	18 (12.2)	9 (8.8)				
Associated handicaps								
Severe motor impairments	Tetraplegia	169 (83.7)	105 (75.5)	53 (53.5)	<10 ⁻³	↘	7.2	
	Paraplegia	32 (15.8)	27 (19.4)	39 (39.4)				↗
	Hemiplegia	1 (0.5)	7 (5)	7 (7.1)				↗
Neurologic impairments	Movement disorders	23 (11)	19 (12.7)	7 (6.7)	0.36	=	1.9	
	Severe dystonia	20 (9.5)	10 (6.8)	3 (3)	0.03	↘	3.4	

	Global hypotonia	54 (25.6)	20 (13.7)	16 (15.7)	0.01	↘	3.2
	Extrapyrarnidal syndrom	51 (24)	22 (15.2)	34 (33.8)	0.20	=	3.2
	Ataxia	6 (3)	1 (0.7)	1 (1)	0.13	=	5.9
Sensorial disorders	Visual impairment	56 (26.5)	39 (25.8)	23 (22.5)	0.47	=	2.1
	Hearing impairment	9 (4.2)	6 (4)	7 (7)	0.35	=	2.3
Behaviorial disorders		161 (74.5)	130 (86.1)	94 (90.4)	<10⁻³	↗	0.6
	Withdrawn	43 (20.1)	30 (20)	40(38.5)	<10⁻³	↗	1.1
	Intermittent screaming	98 (46.2)	105 (69.5)	81 (78)	<10⁻³	↗	1.5
	Intermittent crying	59 (27.7)	71 (47)	40 (38.5)	0.01	↗	1.3
	Agitation	85 (40)	99 (65.6)	58 (55.8)	<10⁻³	↗	1.3
	Self agressivity	24 (11.3)	30 (20)	32 (30.8)	<10⁻³	↗	1.3
	Agressivity	17 (8)	20 (13.2)	8 (7.7)	0.76	=	1.3
	Sterotypies	75 (35.2)	45 (30)	36 (34.6)	0.74	=	1.3
	mericysm	3 (1.4)	4 (2.6)	2 (1.9)	0.64	=	1.3
Sleep disorders	Short sleep	14 (7.1)	17 (11.5)	12 (12)	0.13	=	6.1
	Night wake up	25 (12.6)	22 (15)	17 (17)	0.28	=	5.7
	Difficulties falling asleep	29 (14.6)	24 (16.2)	8 (8)	0.18	=	5.7
2)Comorbidities							
Epilepsy	Presence of epilepsy	123 (56.7)	65 (43.3)	65 (62.5)	0.75	=	0.6
	Previous status epilepticus	50 (23)	25 (16.5)	15 (14.4)	0.007	↘	23
	Drug-resistant epilepsy	31 (14.4)	12 (8.1)	7 (6.8)	0.02	↘	1.3
Orthopedic	Scoliosis	158 (75)	97 (71.3)	54 (55.7)	0.001	↘	6.3

	Limb deformation	177 (82.7)	118 (79.7)	79 (76)	0.15	=	1.7
	Limb fracture	20 (9.4)	8 (5.5)	7 (7.1)	0.38	=	3.4
	Hip luxation	62 (30.5)	47 (32.4)	25 (24.3)	0.36	=	4.9
	Neck stiffness	11 (5.5)	4 (2.7)	2 (1.9)	0.09	=	5.1
	Arthrodesis	72 (36.5)	10 (7.8)	0 (0)	<10⁻³	↘	12.4
	Other surgery	117 (56.5)	55 (39.6) ^o	16 (15.7) ^o	<10⁻³	↘	5.5
Pulmonary	Recurrent pulm. Infections	17 (7.9)	10 (6.8)	4 (4)	0.19	=	1.7
	Aspiration syndrome	51 (23.7)	31 (20.5)	27 (26)	0.80	=	0.8
	Bronchial congestion	49 (22.6)	19 (12.6)	13 (12.5)	0.01	↘	0.4
Digestive	Drooling	72 (34.3)	34 (22.5)	28 (27.2)	0.08	=	2.1
	Multiple caries	9 (5.3)	5 (4.2)	6 (6.4)	0.78	=	19
	Fecal impaction	94 (45.6)	99 (66)	83 (81.4)	<10⁻³	↗	3.4
	Gastroesophageal reflux	88 (42.5)	59 (39.6)	27 (26.2)	0.008	↘	3.2
Urinary	Reccurent urin. tract infection	24 (11)	25 (16.7)	10 (9.6)	0.96	=	0.4
	Urinal retention	8 (3.7)	4 (2.6)	1 (1)	0.17	=	0
	Chronic renal failure	21 (15 ^o)	29 (25.2)	11 (14) ^o	0.81	=	29.3
Cutaneous	Bedsore	15 (7)	10 (6.6)	1 (1)	0.04	↘	0.8
	Pressure fragility	86 (40.2)	83 (55)	48 (46.2)	0.13	=	1.1
Pain		22 (10.1)	37 (24.5)	64 (61.5)	<10⁻³	↗	0.2
Chronic diseases ^a		5 (2.3)	4 (2.7)	4 (3.8)	0.44	=	0.8

^a Chronic diseases: vascular stroke and/or myocardial infarction and/or diabetes and/or cancer: MD missing data

Table 2. Neurodevelopmental status and autonomy of polyhandicaped persons

	18-34 years	35-49 years	50-68 years	p-value	Trends	MD
	N=219	N=151	N=104			%
1. Neurodevelopmental status^a	Med (IQR)	Med (IQR)	Med (IQR)			
Language	3 (2-7)	3 (2-4.5)	2 (2-4)	<10 ⁻³	↘	15.6
Posture-motor ability	3.5 (2-8)	3 (2-5.5)	3 (2-4)	<10 ⁻³	↘	14.5
Coordination	3 (2-6)	3 (2-5)	3 (2-5)	<10 ⁻³	↘	17.3
Sociability	3.5 (2-8)	3 (2-5)	2 (2-3.5)	<10 ⁻³	↘	15.2
2. Autonomy	M±SD	M±SD	M±SD			
FIM score ^b	22.7±6.7	21.5±6.8	21±6.6	<10 ⁻³	↘	2.3

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

^b FIM Functional Independency Measure scores (from 0 to 126)

Med (IQR) median (interquartile range); M±SD mean (standard deviation); MD missing data

Table 3. Medical devices and rehabilitation procedures of polyhandicapped persons

		18-34 years	35-49 years	50-68 years	p- values	Trends	MD %
		N=219 (%)	N=151 (%)	N=104 (%)			
1. Medications							
Number	M±SD	7.5±3.4	8.3±3.4	8.2±2.9	0.01	↗	1.9
Laxatives		175 (87.5)	144 (96.6)	103 (99)	<10 ⁻³	↗	4.4
Anti convulsant		161 (75)	113 (75.8)	77 (74)	0.91	=	1.3
Antalgics		131 (60.4)	103 (68.7)	81 (78)	<10 ⁻³	↗	0.6
Psychotropics		91 (46.2)	116 (78)	89 (86.4)	<10 ⁻³	↗	5.3
Antispastics		67 (33.3)	39 (26.2)	17 (16.5)	<10 ⁻³	↘	4.4
Antidystonics		47 (22.6)	19 (12.8)	5 (4.8)	<10 ⁻³	↘	3
Antibiotics		28 (13.5)	9 (6)	2 (2)	<10 ⁻³	↘	2.5
Osteoporosis prevention		82 (40)	52 (35)	15 (14.4)	<10 ⁻³	↘	3.2
Martial supplementation		35 (17.2)	31 (21.2)	17 (16.3)	0.99	=	4.6
2. Medical devices							
At least one		91 (41.7)	40 (26.5)	24 (23.3)	<10 ⁻³	↘	0.4
Number	M±SD	0.5±0.6	0.3±0.5	0.2±0.4	<10 ⁻³	↘	
Invasive mechanical ventilation		3 (1.4)	0 (0)	0 (0)	0.09	=	0.2
Non-invasive mechanical ventilation		3 (1.4)	3 (2)	0 (0)	0.41	=	0.2
Tracheotomia		8 (3.7)	0 (0)	0(0)	0.006	↘	0.2
Gastrostomy		78 (35.6)	32 (21.2)	22 (21.2)	0.002	↘	0
Permanent urinary probe		1 (0.5)	2 (1.3)	1 (1)	0.53	=	0.2
Cerebro-spinal fluid derivation		7 (3.2)	7 (4.6)	2 (2)	0.67	=	0
Central venous catheter		2 (0.9)	0 (0)	0(0)	0.71	=	0
3 . Rehabilitation procedures							
Sitting device> 3hrs/day		205 (97.6)	147 (98.7)	101 (97.1)	0.90	=	2.3
Bed with orthosis		92 (46.2)	62 (41.6)	36 (34.6)	0.05	↘	4.6
Limb orthosis		94 (50.3)	37 (24.7)	23 (22.3)	<10 ⁻³	↘	7.2
Verticalization device once/day		78 (41.7)	22 (14.8)	15 (14.6)	<10 ⁻³	↘	7.4
Number of transferts (M±SD)		6.2±2	5.7±2	4.2±1.6	<10 ⁻³	↘	7.2
Physiotherapy sessions (Med (IQR))		8 (0-12)	0 (0-8)	0 (0-0)	<10 ⁻³	↘	7.8
Shower 1/day		213 (98.6)	150 (99.3)	103 (100)	0.19	=	0.8
Going out once/day		17 (8.2)	15 (10.2)	8 (7.7)	0.95	=	2.5
Adapted educative care		168 (76.7)	75 (49.7)	28 (27)	<10 ⁻³	↘	0

M±SD mean (standard deviation); Med (IQR) median (interquartile range); MD missing data