



## Research Article

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# ICD-Based Diagnoses Versus Admission Reason-Based Diagnostic Groupings in Out-Of-Hospital Intensive Care: Implications for Nursing-Related Health Services Research

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### Abstract

**Background:** Out-of-hospital intensive care (OHIC) represents a rapidly growing sector in nursing care for patients with chronic critical illness. Patient characteristics are commonly described using ICD-based diagnoses, although their suitability for nursing-related health services research re-mains unclear. **Aim:** To present an admission reason-based diagnostic grouping in OHIC patients and to compare ICD-based diagnoses with an admission reason-based diagnostic grouping system regarding their ability to reflect nursing-relevant patient characteristics in OHIC. **Methods:** A descriptive cross-sectional study was conducted including all patients receiving OHIC from a nationwide German provider (n =1,825). ICD-based diagnoses were compared with a newly implemented, physician-validated admission reason-based diagnostic system. Descriptive statistics and comparative analyses were performed. **Results:** Among 1,825 patients with a clearly defined primary admission reason (PAR), brain impairment (52%) and neurological diseases (25%) were the most frequent reasons for OHIC. Nursing-relevant comorbidities, particularly dysphagia, were documented significantly more often using the admission reason-based system compared to ICD-based documentation. **Conclusion:** Admission reason-based diagnostic groupings better reflect the nursing and clinical realities of OHIC patients than ICD-based diagnoses and provide a robust foundation for nursing-related health services research.

**Keywords:** Out-of-Hospital Intensive care (OHIC); Admission reasons; Secondary diagnoses; Dysphagia

## Introduction

Out-of-hospital intensive care (OHIC) has become an essential component of nursing care for patients with chronic critical illness who require long-term ventilation, tracheostomy care, or complex medical and nursing support [1]. Advances in medical technology since the late 20<sup>th</sup> century have enabled a shift of intensive care from hospital settings to patients' homes or shared living facilities [2].

Despite the growing relevance of OHIC, empirical knowledge about patient characteristics remains limited. Patient populations are commonly described using ICD-based diagnoses, which are primarily designed for epidemiological surveillance [3] and reimbursement purposes [4]). Their suitability for reflecting nursing-relevant care needs in OHIC has rarely been examined.

ICD classifications often fail to capture functional impairments, care complexity and clinically relevant comorbidities that strongly influence nursing workload and care planning [4,5]. This gap is particularly relevant in OHIC, where patients frequently present with heterogeneous diagnoses, varying severity of impairment and long-term care trajectories [6].

The present study addresses this gap by comparing ICD-based diagnoses with a newly developed, admission reason-based diagnostic grouping system specifically designed to reflect nursing and medical care needs in OHIC.

## Aim

The aim of this study was to evaluate whether an admission reason-based diagnostic grouping system provides a more accurate and nursing-relevant description of OHIC patients compared to ICD-based diagnoses.

## Material and Methods

### Study design and data source

A descriptive cross-sectional study was conducted using anonymized secondary data from a nationwide German OHIC provider. All patients receiving OHIC in individual home care or shared living facilities on 23 June 2025 were included. For technical reasons, the percentages for variables dysphagia, ventilation and tracheostomy can only be given for a small part of the total sample (Region South East and South West, n=307). ICD-10 data for dysphagia (R13) on 1,289 clients from June 2021 was used to compare former ICD-based documentation to documentation of dysphagia in the new admission reason-based system.

## Study population

The provider delivers OHIC across all regions of Germany and serves patients independent of socioeconomic status, insurance type or place of residence. The population can therefore be considered broadly representative of OHIC patients in Germany.

## Admission reason-based diagnostic system

In 2022, the provider replaced ICD-based diagnostic documentation with an admission reason-based system.

- Primary admission reasons (PAR) define the underlying condition leading to OHIC and remain constant throughout care.
- Secondary diagnoses represent comorbidities and care-relevant conditions that may change over time.
- Both components were physician-validated. Nursing-relevant parameters such as ventilation, dysphagia and tracheostomy were systematically recorded.

## Statistical analysis

Absolute and relative frequencies were calculated for primary admission reasons, secondary diagnoses, sex, age groups and care setting. 95% confidence intervals were calculated for primary admission reasons and secondary diagnoses. Mean and standard deviation was calculated for age. Differences in dysphagia documentation before and after implementation of the new system were analysed using 95% confidence intervals. Differences in proportions of primary admission reasons for individual home care (IHC) and Shared Living Facility (SLF) were analysed using 95% confidence intervals. Mean age in IHC and SLF was compared using 95% confidence intervals. Number of secondary diagnoses by care setting and by primary admission reason (PAR) were compared using confidence intervals. Analyses were conducted using R version 4.5.0.

## Ethics

As only anonymized secondary data were analysed, ethical approval and informed consent were not required.

## Results

### Sociodemographic and Care-Related Characteristics

A total of 1,825 patients receiving out-of-hospital intensive care were included in the analysis. The mean age was 52 years (SD 24.4). Overall, 14.7% (n = 269) were younger than 18 years, 14.8% (n = 271) were aged 18–40 years, 32.8% (n = 599) were aged 41–65 years and 37.6% (n = 686) were older than 65 years (Table 1).

More than half of the patients were cared for in shared living facilities (SLF; 55%, n = 1,003) while 45% (n = 822) received individual home care (IHC). The majority were male (59.8%, n = 1,092), 36.5% were female (n = 667) and 3.6% (n = 66) were categorized as unknown.

Age: Mean (SD)	52 ( 24.4 )
Age groups: n (%)	
< 18 years	269 ( 14.7 )
18-40 years	271 ( 14.8 )
41-65 years	599 ( 32.8 )
> 65 years	686 ( 37.6 )
Care Setting: n (%)	
Individual home care (IHC)	822 ( 45.0 )
Shared living facility (SLF)	1003 ( 55.0 )
Sex: n (%)	
Female	667 ( 36.5 )
Male	1092 ( 59.8 )
Unknown	66 ( 3.6 )

**Table 1:** Sociodemographic and care-related characteristics of patients receiving out-of-hospital intensive care (n = 1825).

### Primary Admission Reason Grouping

Regarding primary admission reason (PAR), brain impairment (PAR 1) was the most frequent diagnostic group, accounting for 51.5% (n = 940) of cases. Neuromuscular diseases (PAR 2) comprised 24.7% (n = 450), followed by lung and respiratory diseases (PAR4) with 15.3% (n = 279). Spinal cord injury (SCI; PAR3) represented 4.8% (n = 88). Less frequent causes included heart diseases (PAR5; 2.1%, n = 39), tumour diseases not affecting the lungs or respiratory tract (PAR6; 1.0%, n = 18), metabolic disorders (PAR8; 0.4%, n = 8) and orthopaedic-surgical indications (PAR7; 0.2%, n = 3, Table 2).

	n (%)
PAR 1: Brain impairment	940 (51.5)
PAR2: Neuromuscular diseases	450 (24.7)
PAR3: Spinal Cord Injury (SCI) / Tetraplegia - Paraplegia	88 (4.8)
PAR4: Lung and respiratory diseases	279 (15.3)
PAR5: Heart diseases	39 (2.1)
PAR6: Tumour diseases (not affecting the lungs or respiratory tract)	18 (1)
PAR7: Orthopaedic-surgical reasons (e.g. scoliosis)	3 (0.2)
PAR8: Metabolic disorders (e.g. type 1 diabetes mellitus)	8 (0.4)
Total	1825 (100)

**Table 2:** Structure of the primary admission reason grouping system used in out-of-hospital intensive care.

Within the detailed diagnostic categories, traumatic brain injury (7.8%), COPD (6.5%) amyotrophic lateral sclerosis (ALS; 5.1%), spinal cord injury (SCI; 4.8%), hypoxic brain injury (2.7%), multiple sclerosis (MS; 1.8%) and other respiratory disorders (8.8%) were among the most prevalent specified conditions (Table 6).

Admission to out-of-hospital intensive care most frequently originated from neurological rehabilitation centres (51.5%), followed by neuromuscular and SCI centres (29.5%), specialized pulmonology clinics (15.3%) and other medical disciplines (3.7%, Table 3).

	n(%)
Neurological rehabilitation centre	940 ( 51.5 )
Neuromuscular and/or SCI centre	538 ( 29.5 )
Specialized clinics for pulmonology	279 ( 15.3 )
Other medical conditions	68 ( 3.7 )
Total	1825 ( 100 )

**Table 3:** Distribution of reasons for admission to out-of-hospital intensive care by medical disciplines.

### Secondary Nursing-Relevant Diagnoses

Secondary nursing-relevant diagnoses were common. PEG was present in 72% of patients. Arterial hypertension and epilepsy were each present in 22% of patients (Table 7).

Data on dysphagia, ventilation and tracheostomy was only available for a subpopulation (South East, South West, n=307). 90% of these clients had tracheostomy, 29% were ventilated (82% of these are invasively ventilated, 52% of these are ventilated 24 hours, table not shown).

Dysphagia was documented significantly more often after implementation of the admission reason-based system (85%[81%;

89%]) compared to ICD-based documentation 16%[14%; 18%] (table not shown).

Region South East and South West differ from the total sample in terms of a higher proportion of older people (41-65 years: 40% (total sample 31%), > 65 years: 45 % (total sample 38%), a higher proportion of clients with brain impairments (60% versus 52% in the total sample) and a lower proportion of clients with neuromuscular disorders (18% versus 25% in the total sample, table not shown).

### Primary Admission Reasons (PAR) by Care Setting

When examining the distribution of admission groups within care settings patients in SLF were more frequently diagnosed with brain impairment (59.4%; 95% CI 56.4–62.5) compared to IHC (41.8%; 95% CI 38.5–45.2). In contrast, neuromuscular diseases were more prevalent in IHC (37.6%; 95% CI 34.3–40.9) than in SLF (14.1%; 95% CI 11.9–16.2). Lung and respiratory diseases were more common in SLF (18.0%; 95% CI 15.7–20.4) than in IHC (11.9%; 95% CI 9.7–14.1).

(Confidence intervals did not overlap between care settings, indicating statistically significant differences. Table 4)

	Individual home care (IHC)	Shared living facility (SLF)
PAR1: Brain impairment	41.8 ( 38.5 , 45.2 )	59.4 ( 56.4 , 62.5 )
PAR2: Neuromuscular diseases	37.6 ( 34.3 , 40.9 )	14.1 ( 11.9 , 16.2 )
PAR3: Spinal Cord Injury (SCI)	5.6 ( 4 , 7.2 )	4.2 ( 2.9 , 5.4 )
PAR4: Lung and respiratory diseases	11.9 ( 9.7 , 14.1 )	18 ( 15.7 , 20.4 )
PAR5: Heart diseases	1.2 ( 0.5 , 2 )	2.9 ( 1.9 , 3.9 )
PAR6: Tumour diseases (not affecting the lungs or respiratory tract)	0.6 ( 0.1 , 1.1 )	1.3 ( 0.6 , 2 )
PAR7: Orthopaedic-surgical reasons (e.g. scoliosis)	0.2 ( 0 , 0.6 )	0.1 ( 0 , 0.3 )
PAR8: Metabolic disorders (e.g. type 1 diabetes mellitus)	1.0 ( 0.3 , 1.6 )	0.0 (0.0,0.0)
Confidence Interval in brackets		

**Table 4:** Primary admission reason by type of care.

Frequencies of care setting within each admission group showed that patients with brain impairment were predominantly treated in SLF (63.4%; 95% CI 60.3–66.5), whereas patients with neuromuscular diseases were more often cared for in IHC (68.7%; 95% CI 64.2–73.1). Patients with lung and respiratory diseases were primarily managed in SLF (64.9%; 95% CI 59.3–70.5). For heart diseases (PAR5), 74.4% (95% CI 69.2–79.5) were treated in SLF, whereas slightly more than half of SCI patients lived in IHC (52.3% (95% CI 41.8–62.7, table not shown).

#### Number of Secondary Diagnoses by PAR and Care Setting

The mean number of secondary diagnoses was 3.4 in the total cohort and differed by PAR group. Patients with brain impairment had a mean of 3.7 secondary diagnoses (95% CI 3.5–3.8) compared with 2.8 (95% CI 2.6–3.0) among those with neuromuscular diseases. The confidence intervals were non-overlapping, indicating a statistically significant difference. Patients with spinal cord injury (mean 3.4; 95% CI 2.9–3.9), lung and respiratory diseases (mean 3.6; 95% CI 3.3–4.0) and heart diseases (mean 3.5; 95% CI 2.6–4.3) showed comparable levels of multimorbidity (Table 5).

	Mean number of secondary diagnoses (confidence interval)
PAR1: Brain impairment	3.7 ( 3.5 , 3.8 )
PAR2: Neuromuscular diseases	2.8 ( 2.6 , 3.0 )
PAR3: Spinal Cord Injury (SCI)	3.4 ( 2.9 , 3.9 )
PAR4: Lung and respiratory diseases	3.6 ( 3.3 , 4.0 )
PAR5: Heart diseases	3.5 ( 2.6 , 4.3 )

**Table 5:** Average values of secondary diagnoses (SD) by primary admission reason.

A marked difference was observed between care settings. Patients in SLF had a significantly higher mean number of secondary diagnoses (4.0; 95% CI 3.9–4.2) compared to those in IHC (2.7; 95% CI 2.5–2.8) as indicated by non-overlapping confidence intervals (table not shown).

#### Age Differences by Care Setting

Patients in SLF were substantially older (mean 61.9 years; 95% CI 60.9–62.9) than those receiving IHC (mean 40.0 years; 95% CI 38.1–41.9, table not shown).

#### Detailed Distribution of Primary Admission Reasons by Admission Group (Relative frequencies in this section refer to the total cohort (Table 6))

	n (%)
PAR: 1 Brain impairment / 1 Trauma / 1 Accident	88 ( 4.8 )
PAR: 1 Brain impairment / 1 Trauma / 2 Surgery	13 ( 0.7 )
PAR: 1 Brain impairment / 1 Trauma / 3 During childbirth	44 ( 2.4 )
PAR: 1 Brain impairment / 1 Trauma / 4 Suicide attempts	7 ( 0.4 )
PAR: 1 Brain impairment / 1 Trauma / 5 Attempted murders	4 ( 0.2 )
PAR: 1 Brain impairment / 1 Trauma / 6 Hypoxia	50 ( 2.7 )
PAR: 1 Brain impairment / 1 Trauma / 7 Others	47 ( 2.6 )
PAR: 1 Brain impairment / 1 Trauma / 8 Undefined cause	20 ( 1.1 )
PAR: 1 Brain impairment / 2 Non-traumatic / 1 Ischemic stroke	177 ( 9.7 )
PAR: 1 Brain impairment / 2 Non-traumatic / 2 Cerebral haemorrhage	221 ( 12.1 )
PAR: 1 Brain impairment / 2 Non-traumatic / 3 Aneurysm	28 ( 1.5 )
PAR: 1 Brain impairment / 2 Non-traumatic / 4 Tumour	14 ( 0.8 )
PAR: 1 Brain impairment / 2 Non-traumatic / 5 Inflammation	7 ( 0.4 )
PAR: 1 Brain impairment / 2 Non-traumatic / 6 Hypoxia	57 ( 3.1 )
PAR: 1 Brain impairment / 2 Non-traumatic / 7 Others	133 ( 7.3 )
PAR: 1 Brain impairment / 2 Non-traumatic / 8 Undefined cause	13 ( 0.7 )
PAR: 1 Brain impairment / Unclear	17 ( 0.9 )

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PAR: 2 Neuromuscular diseases / 1 ALS	93 ( 5.1 )
PAR: 2 Neuromuscular diseases / 2 MS	33 ( 1.8 )
PAR: 2 Neuromuscular diseases / 3 SMA	22 ( 1.2 )
PAR: 2 Neuromuscular diseases / 4 Muscle disease	53 ( 2.9 )
PAR: 2 Neuromuscular diseases / 5 Metabolic disorder	19 ( 1 )
PAR: 2 Neuromuscular diseases / 6 Other genetic defect	66 ( 3.6 )
PAR: 2 Neuromuscular diseases / 7 Others	146 ( 8 )
PAR: 2 Neuromuscular diseases / 8 Undefined cause	18 ( 1 )
PAR: 3 Spinal cord injury / 1 Trauma / 1 Paraplegia	17 ( 0.9 )
PAR: 3 Spinal cord injury / 1 Trauma / 2 Tetraplegia	40 ( 2.2 )
PAR: 3 Spinal cord injury / 2 Non-traumatic / 1 Paraplegia	4 ( 0.2 )
PAR: 3 Spinal cord injury / 2 Non-traumatic / 2 Tetraplegia	9 ( 0.5 )
PAR: 3 Spinal cord injury / 3 Congenital / 2 Tetraplegia	1 ( 0.1 )
PAR: 3 Spinal cord injury / 4 Undefined cause / 1 Paraplegia	4 ( 0.2 )
PAR: 3 Spinal cord injury / 4 Undefined cause / 2 Tetraplegia	13 ( 0.7 )
PAR: 4 Lung and respiratory diseases / 1 COPD	119 ( 6.5 )
PAR: 4 Lung and respiratory diseases / 2 Tumour	31 ( 1.7 )
PAR: 4 Lung and respiratory diseases / 6 Covid-related	9 ( 0.5 )
PAR: 4 Lung and respiratory diseases / 7 Others	113 ( 6.2 )
PAR: 4 Lung and respiratory diseases / Respiratory insufficiency	1 ( 0.1 )
PAR: 4 Lung and respiratory diseases / Undefined cause	6 ( 0.3 )
PAR: 5 Heart / 1 Insufficiency	14 ( 0.8 )
PAR: 5 Heart / 2 Arrhythmia	6 ( 0.3 )
PAR: 5 Heart / 4 Others	17 ( 0.9 )
PAR: 5 Heart / Undefined cause	2 ( 0.1 )
PAR: 6 Tumour diseases (not affecting the lungs or respiratory tract)	18 ( 1.0 )
PAR: 7 Orthopaedic-surgical reasons (e.g. scoliosis)	3 ( 0.2 )
PAR: 8 Metabolic disorders (e.g. type 1 diabetes mellitus)	8 ( 0.4 )

**Table 6:** Primary admission reason (PAR).

### **PAR1: Brain Impairment**

Brain impairment comprised 51.5% (n=940) of the total cohort and was further subdivided into traumatic and non-traumatic causes.

#### **Traumatic Brain Injury**

Traumatic aetiologies accounted for a substantial proportion of PAR1 cases. The most frequent traumatic cause was accident-related brain injury (4.8%), followed by hypoxic injury (2.7%), other traumatic causes (2.6%) and injury during childbirth (2.4%). Less frequent causes included surgery-related trauma (0.7%), suicide attempts (0.4%), attempted homicide (0.2%) and undefined traumatic causes (1.1%).

#### **Non-Traumatic Brain Injury**

Among non-traumatic causes cerebral haemorrhage was the most common (12.1%) followed by ischemic stroke (9.7%). Other relevant aetiologies included unspecified non-traumatic causes (7.3%), non-traumatic hypoxia (3.1%), aneurysm (1.5%), tumour (0.8%), inflammation (0.4%) and undefined non-traumatic causes (0.7%). In 0.9% of cases the underlying mechanism of brain impairment remained entirely unclear.

Overall, vascular events (ischemic stroke and cerebral haemorrhage combined) represented the largest subgroup within PAR1.

### **PAR2: Neuro- and Muscular Diseases**

Neuromuscular diseases accounted for 24.7% (n=450) of the cohort and showed substantial etiological heterogeneity.

The most frequently documented condition was categorized as “other neuromuscular diseases” (8.0%), followed by amyotrophic lateral sclerosis (ALS; 5.1%) and other genetic defects (3.6%). Additional diagnoses included unspecified muscle diseases (2.9%), multiple sclerosis (1.8%), spinal muscular atrophy (SMA; 1.2%), metabolic disorders (1.0%) and undefined causes (1.0%).

Degenerative and genetic neuromuscular disorders therefore constituted the majority within PAR2.

### **PAR3: Spinal Cord Injury (SCI)**

Spinal cord injury (4.8% of the total cohort) was differentiated by aetiology and neurological level.

Traumatic tetraplegia was the most frequent subtype (2.2%), followed by traumatic paraplegia (0.9%). Non-traumatic tetraplegia (0.5%) and non-traumatic paraplegia (0.2%) were less common. Cases with undefined aetiology included tetraplegia (0.7%) and paraplegia (0.2%). Congenital tetraplegia was rare (0.1%).

Overall, traumatic causes predominated within PAR3, particularly those leading to tetraplegia.

### **PAR4: Lung and Respiratory Diseases**

Lung and respiratory diseases accounted for 15.3% (n = 279) of the cohort.

Chronic obstructive pulmonary disease (COPD) was the leading diagnosis (6.5%), closely followed by other respiratory disorders (6.2%). Respiratory tumours accounted for 1.7%, and COVID-19-related respiratory disease for 0.5%. Isolated respiratory insufficiency (0.1%) and undefined causes (0.3%) were rare.

Thus, chronic non-malignant respiratory diseases represented the predominant subgroup within PAR4.

### **PAR5: Heart Diseases**

Heart diseases comprised 2.1% of cases (n = 39). The most frequent conditions were other cardiac disorders (0.9%) and heart insufficiency (0.8%) followed by arrhythmias (0.3%) and undefined cardiac causes (0.1%).

### **PAR6–PAR8: Less Frequent Admission Groups**

Tumour diseases not affecting the respiratory tract accounted for 1.0% of cases. Orthopaedic surgical indications (e.g., scoliosis) represented 0.2% and metabolic disorders (e.g., type 1 diabetes mellitus) 0.4% of the cohort.

Secondary Diagnoses for the total cohort (Table 7)

	<b>n (%[Confidence Interval])</b>
SD: PEG tube inserted	1309 ( 71.7 [ 69.7 , 73.8])
SD: Hypertension	399 ( 21.9 [ 20.0 , 23.8 ])
SD: Epilepsy	398 ( 21.8 [ 19.9 , 23.7 ])
SD: Heart disease	331 ( 18.1 [ 16.4 , 19.9 ])
SD: Lung disease	249 ( 13.6 [ 12.1 , 15.2 ])
SD: Diabetes mellitus (summarized)	224 ( 12.3 [ 10.8 , 13.8 ])
SD: Stomach/intestinal disorder	222 ( 12.2 [ 10.7 , 13.7 ])
SD: Psychiatric illness	187 ( 10.2 [ 8.9 , 11.6 ])
SD: Congenital physical impairment	184 ( 10.1 [ 8.7 , 11.5 ])
SD: Spasticity (summarized)	164 ( 9 [ 7.7 , 10.3 ])
SD: Nerve disorder	163 ( 8.9 [ 7.6 , 10.2 ])
SD: Vascular disease	154 ( 8.4 [ 7.2 , 9.7 ])
SD: Kidney disease	153 ( 8.4 [ 7.1 , 9.7 ])
SD: Congenital mental impairment	151 ( 8.3 [ 7 , 9.5 ])
SD: Bone/skeletal disease	148 ( 8.1 [ 6.9 , 9.4 ])
SD: Pain disorder	140 ( 7.7 [ 6.5 , 8.9 ])
SD: Thyroid disorder	121 ( 6.6 [ 5.5 , 7.8 ])
SD: Mild spasticity	112 ( 6.1 [ 5.0 , 7.2 ])
SD: Diabetes mellitus (insulin-treated)	108 ( 5.9 [ 4.8 , 7.0 ])
SD: Allergies	102 ( 5.6 [ 4.5 , 6.6 ])
SD: Urinary tract disorders	102 ( 5.6 [ 4.5 , 6.6 ])
SD: Obesity, BMI >30	89 ( 4.9 [ 3.9 , 5.9 ])
SD: Diabetes mellitus (unspecified)	84 ( 4.6 [ 3.6 , 5.6 ])
SD: Nicotine abuse	73 ( 4.0 [ 3.1 , 4.9 ])
SD: Eye disease	70 ( 3.8 [ 3.0 , 4.7 ])
SD: Alcohol abuse	58 ( 3.2 [ 2.4 , 4.0 ])
SD: Malignant tumour (no palliative setting)	43 ( 2.4 [ 1.7 , 3.1 ])
SD: Severe spasticity	40 ( 2.2 [ 1.5 , 2.9 ])
SD: COPD grade 3+4	33 ( 1.8 [ 1.2 , 2.4 ])
SD: Diabetes mellitus (tablets-treated)	29 ( 1.6 [ 1.0 , 2.2 ])
SD: Liver disease	29 ( 1.6 [ 1.0 , 2.2 ])
SD: Drug/medication abuse	24 ( 1.3 [ 0.8 , 1.8 ])
SD: Social/cultural characteristics	20 ( 1.1 [ 0.6 , 1.6 ])
SD: COPD grade 1+2	15 ( 0.8 [ 0.4 , 1.2 ])
SD: Hypotension	15 ( 0.8 [ 0.4 , 1.2 ])
SD: Stoma/colostomy	14 ( 0.8 [ 0.4 , 1.2 ])
SD: Biliary disease	12 ( 0.7 [ 0.3 , 1.0 ])
SD: Pancreatic disease	12 ( 0.7 [ 0.3 , 1.0 ])

SD: Spasticity (unspecified)	12 ( 0.7 [ 0.3 , 1.0 ] )
SD: Malignant tumor, unspecified	10 ( 0.5 [ 0.2 , 0.9 ] )
SD: Malignant tumor with palliative setting	8 ( 0.4 [ 0.1 , 0.7 ] )
SD: Benign tumor	6 ( 0.3 [ 0.1 , 0.6 ] )
SD: Spleen disease	4 ( 0.2 [ 0.0 , 0.4 ] )
SD: Diabetes mellitus (insulin + tablets-treated)	3 ( 0.2 [ 0.0 , 0.4 ] )

**Table 7:** Secondary diagnoses (total cohort), sorted by occurrence, multiple entries possible.

Secondary diagnoses were highly prevalent among patients receiving out-of-hospital intensive care. Overall, 71.7% of patients (n = 1,309) had a percutaneous endoscopic gastrostomy (PEG) tube. Common comorbidities included hypertension (21.9%, n = 399), epilepsy (21.8%, n = 398), heart disease (18.1%, n = 331), lung disease (13.6%, n = 249) and diabetes mellitus (12.3%, n = 224). Gastrointestinal disorders were present in 12.2% (n = 222) and psychiatric illnesses affected 10.2% (n = 187). Congenital physical impairments were documented in 10.1% (n = 184) and spasticity in 9.0% (n = 164).

Other neurological or systemic comorbidities included nerve disorders (8.9%, n = 163), vascular disease (8.4%, n = 154), kidney disease (8.4%, n = 153), congenital mental impairment (8.3%, n = 151) and bone or skeletal disease (8.1%, n = 148). Pain disorders (7.7%, n = 140) and thyroid disorders (6.6%, n = 121) were also reported. A small proportion of patients (6.6%, n = 120) had no secondary diagnoses documented.

Additional less frequent conditions included mild spasticity (6.1%), insulin-dependent diabetes mellitus (5.9%), allergies and urinary tract disorders (5.6% each). Obesity (BMI >30) was documented in 4.9%. Other metabolic or endocrine disorders, substance use, ophthalmologic disease, malignant tumours and severe spasticity were each present in ≤3% of the cohort. Rare conditions (<1%) included biliary or pancreatic disease, stomas, COPD grades 1–2, hypotension and various unspecified or palliative tumours.

Overall, these data demonstrate a high burden of multimorbidity among patients receiving out-of-hospital intensive care with a predominance of PEG use, neurological conditions, cardiovascular and metabolic comorbidities.

### Secondary Diagnoses by PAR and Care Setting (tables not shown)

Secondary diagnoses were prevalent across all admission groups (PAR1–PAR5), reflecting high multimorbidity and complex care needs in patients receiving out-of-hospital intensive care (n = 1825). The distribution and type of secondary diagnoses differed notably between admission groups and care settings.

### PAR1: Brain Impairment (n = 940)

Patients with brain impairment exhibited a high prevalence of PEG tube insertion (81.7%, 95% CI 79.2–84.2). Neurological comorbidities were common, with epilepsy in 29.7% (95% CI 26.8–32.6) and spasticity in 11.9% (95% CI 9.8–14.0). Cardiovascular conditions included hypertension (28.1%, 95% CI 25.2–31.0) and heart disease (18.4%, 95% CI 15.9–20.9) while pulmonary and metabolic comorbidities affected 13.8% and 13.5% of patients. Gastrointestinal disorders (13.0%, 95% CI 10.8–15.1), psychiatric illness (9.9%, 95% CI 8.0–11.8) and vascular disease (9.3%, 95% CI 7.4–11.1) were also present.

### PAR2: Neuromuscular Diseases (n = 450)

In patients with neuromuscular diseases PEG tubes were inserted in 65.1% (95% CI 60.7–69.5) and congenital physical impairments affected 21.6% (95% CI 17.8–25.4). Epilepsy (17.6%, 95% CI 14.0–21.1) was a notable neurological secondary diagnosis while congenital mental impairment occurred in 14.2% (95% CI 11.0–17.4). Pulmonary (13.6%), cardiovascular (heart disease 12.9%; hypertension 8.4%) and musculoskeletal comorbidities (bone/skeletal disease 12.0%; nerve disorders 10.7%) were also present. Notably, 9.6% of patients had no rec-order secondary diagnoses.

### PAR3: Spinal Cord Injury (n = 88)

Among spinal cord injury patients, half (50.0%, 95% CI 39.6–60.4) had a PEG tube. Spasticity was observed in 22.7% (95% CI 14.0–31.5) with mild and severe forms in 15.9% and 3.4%. Gastrointestinal disorders (20.5%) and lung disease (19.3%) were frequent. Neurological (epilepsy 12.5%), cardiovascular (heart disease 12.5%; hypertension 14.8%) and urinary tract comorbidities (14.8%) were also present, along with obesity, bone/skeletal, kidney and psychiatric disorders. Only 6.8% had no secondary diagnoses.

### PAR4: Lung and Respiratory Diseases (n = 279)

Patients with lung diseases had PEG tubes in 57.7% (95% CI 51.9–63.5). Cardiovascular comorbidities were frequent such as heart disease (26.2%) and hypertension (25.8%). Psychiatric illness

affected 16.8%, diabetes mellitus 16.1% and kidney disease 16.1%. Gastrointestinal disorders were present in 13.6%, lung disease in 12.5% and nicotine abuse in 11.1%. Less common secondary diagnoses (<10%) included vascular and nerve disorders, thyroid disease, pain, obesity, epilepsy and congenital impairments.

#### **PAR5: Heart Diseases (n = 39)**

In the small cohort of patients with heart diseases, PEG insertion and cardiovascular comorbidities were common but data were limited due to sample size. Hypertension and heart disease were the primary secondary diagnoses, while metabolic, neurological and other comorbidities occurred less frequently.

#### **Care Setting: Individual Home Care (IHC) vs Shared Living Facility (SLF)**

Patients receiving individual home care (IHC, n = 822) and those in shared living facilities (SLF, n = 1003) exhibited differences in secondary diagnoses burden.

IHC patients showed higher prevalence of spasticity (unspecified: 61.9%) and neurological comorbidities, including epilepsy (23.5%) and congenital physical or mental impairments (16.3% and 12.7%). Cardiovascular, pulmonary and metabolic comorbidities were less frequent than in SLF patients.

SLF patients had higher overall multimorbidity with PEG tubes, cardiovascular diseases and metabolic disorders more common. This is consistent with their older mean age (61.9 vs 40.0 years in IHC) and the predominance of AG1 and AG4 diagnoses in SLF settings.

Overall, secondary diagnoses in out-of-hospital intensive care patients reveal high prevalence of PEG use, neurological disorders, spasticity, cardiovascular and metabolic comorbidities.

#### **Discussion**

This study provides comprehensive insights into the population of patients receiving out-of-hospital intensive care (OHIC) and highlights the marked heterogeneity of this group, as well as substantial structural differences between care settings. By combining clinically informed diagnostic grouping with detailed analysis of secondary diagnoses, the findings offer important implications for clinical practice, nursing care and health policy within the evolving German regulatory framework.

#### **Principal Findings and Interpretation**

A key finding is the predominance of neurological conditions as the primary reason for admission to out-of-hospital intensive care. More than half of the patients were classified within the brain impairment group (51.5%), followed by neuromuscular diseases (24.7%) and respiratory conditions (15.3%). Within the brain

impairment group, vascular events - particularly ischemic stroke and intracerebral haemorrhage - constituted the largest subgroup. This distribution is consistent with previous literature identifying acquired brain injury as a major driver of long-term intensive care dependency and prolonged need for ventilatory support [7,8].

Clear differences emerged between care settings. Patients with brain impairment and respiratory diseases were predominantly treated in shared living facilities (SLF), whereas those with neuromuscular diseases were more frequently managed in individual home care (IHC). These findings align with known disease trajectories. Neuromuscular disorders are often characterized by progressive physical decline with relatively preserved cognition, enabling home-based care, whereas acquired brain injuries frequently result in severe cognitive and functional impairment requiring more structured care environments [9,10].

Importantly, only 29% of the study population were invasively or non-invasively ventilated. This finding challenges the common perception of OHIC as a predominantly ventilation-driven care sector and suggests that a substantial proportion of patients require intensive care primarily due to neurological impairment, functional dependency and complex nursing needs rather than respiratory failure alone. This observation aligns with emerging evidence that the concept of chronic critical illness extends beyond mechanical ventilation and includes a broader spectrum of long-term care dependency [11,12].

#### **Advantages of Admission Reason-Based Diagnostic Grouping**

A key methodological strength of this study is the use of clinically defined admission groups rather than relying solely on ICD-based classifications. While ICD-coding is indispensable for epidemiological and administrative purposes, it primarily reflects discrete etiological diagnoses and may insufficiently capture functional impairment, which is a major determinant of long-term care needs [12–14].

By aggregating diagnoses into eight clinically reasonable categories such as brain impairment, neuromuscular diseases, spinal cord injury and chronic respiratory disease, the present approach integrates both underlying pathophysiology and functional consequences. This strategy is consistent with established approaches in health services research, including hierarchical condition categories and comorbidity groupings, which have been shown to enhance care settings, interpretability and reduce heterogeneity in large datasets [15–17].

This classification enables a more clinically relevant representation of care complexity by linking diagnostic categories with functional status, care requirements and resource utilization. For example, diverse aetiologies of brain impairment - such as traumatic brain

injury, hypoxic injury and stroke - associated common long-term care needs, including dysphagia management, PEG dependence, and neurorehabilitation. Grouping these conditions therefore avoids artificial fragmentation of clinically comparable populations and facilitates reasonable comparisons across care settings [12,15,16].

Notably, a substantial discrepancy was observed in the identification of dysphagia depending on the data source. Accurate identification of dysphagia is of particular importance, as it directly influences key aspects of care, including PEG placement, aspiration risk and overall nursing workload. Dysphagia is a well-established predictor of complications and resource utilization in neurologically impaired populations [10,18,19]. While clinical assessment and supplementary data indicated that 85% of patients were affected, ICD-based analysis identified dysphagia in only 16% of cases. This gap underlines the limitations of administrative coding in capturing clinically relevant functional impairments and further supports the added value of admission reason-based classification approaches [12,13,15,20].

Underestimation in ICD-based datasets may therefore result in incomplete assessment of patient needs, inadequate staffing models and a systematic underrepresentation of care complexity in out-of-hospital intensive care populations.

### **Multimorbidity and Care Complexity**

Another central finding is the high prevalence of multimorbidity across the cohort. The mean number of secondary diagnoses was substantial and significantly higher in patients with brain impairment compared to those with neuromuscular diseases. The high prevalence of PEG feeding, dysphagia and tracheostomy reflects the complexity of long-term intensive care populations and is consistent with previous studies on chronically critically ill patients [11,12].

Common comorbidities included arterial hypertension and epilepsy. The overall incidence of multimorbidity observed in this study supports prior findings that patients requiring long-term ventilation represent a highly complex population with extensive medical and nursing needs [21].

Importantly, multimorbidity differed significantly between care settings. Patients in SLF exhibited a markedly higher number of secondary diagnoses compared to those receiving IHC. This corresponds with the higher mean age in SLF and supports the concept that institutionalized care settings disproportionately serve older and more medically complex patients [2,21].

The finding that just 29% of the patients are ventilated further emphasizes that nursing work-load in OHIC is not primarily

defined by ventilation management but by the complexity of multimorbidity, functional impairment and long-term dependency in the presence of a tracheostomy. This has important implications for training, staffing and competency frameworks, which should extend beyond respiratory care.

### **Age Distribution and Structural Care Patterns**

The age distribution demonstrates a wide spectrum with a substantial proportion of both younger and older patients, although more than one-third were aged over 65 years. The pronounced age difference between care settings suggests structural selection mechanisms: Younger patients are more frequently managed at home, while older and more multimorbid individuals are more often treated in shared living facilities.

These differences likely reflect not only clinical characteristics but also social determinants, such as the availability of informal caregivers and family support. Previous research has high-lighted the critical role of social context and caregiver resources in enabling home-based long-term ventilation [1].

### **Care Pathways and System-Level Implications**

More than half of the patients were transferred to out-of-hospital intensive care from neurological rehabilitation settings, highlighting the importance of this transition interface. This finding is consistent with prior studies showing that out-of-hospital ventilation often represents a continuation of care following acute illness and rehabilitation rather than a primary care setting [7,14].

The clustering of specific diagnostic groups within particular care settings suggests the presence of implicit allocation mechanisms. However, these appear to be only partially standardized and may be influenced by structural and historical factors rather than clear clinical criteria. This observation aligns with ongoing discussions about the need for improved care coordination and standardized pathways in long-term ventilation care [15].

### **Implications of Secondary Diagnoses for Nursing Practice in OHIC**

The detailed analysis of secondary diagnoses provides clinically meaningful insights into the specific care demands faced by nurses in out-of-hospital intensive care and highlights the importance of diagnosis-informed care planning. Across all admission groups, the high prevalence of multimorbidity confirms that nursing care in OHIC extends far beyond the management of a single primary condition and instead requires continuous prioritization, coordination and adaptation to complex and interacting health needs.

Patients with brain impairment (PAR1), who represent the largest subgroup, exhibit a particularly demanding care profile characterized by high rates of PEG dependence, dysphagia and epilepsy. For nursing practice, this translates into a combination of intensive nutritional management, aspiration prevention, seizure monitoring, and strict infection control procedures. The coexistence of neurological deficits and cardiovascular comorbidities further increases the need for continuous clinical assessment and early detection of deterioration. These findings reinforce previous evidence that neurologically impaired patients require highly skilled nursing care with a strong focus on complication prevention and long-term functional management [12,18].

In contrast, patients with neuromuscular diseases (PAR2) present a different but equally complex care profile. Although multimorbidity is comparatively lower, the higher prevalence of congenital impairments and progressive physical decline requires long-term continuity of care, patient-specific adaptation of assistive technologies and a strong emphasis on preserving autonomy. For nurses, this implies a shift from acute complication management toward long-term disease trajectory management and psychosocial support which has been identified as a core component of care in this population [1,9].

Patients with spinal cord injury (PAR3) highlight the importance of managing secondary complications such as spasticity, gastrointestinal dysfunction, and urinary tract disorders. These conditions are closely linked to daily nursing interventions, including positioning, bowel and bladder management, and prevention of secondary complications. The high variability of comorbidities in this group underscores the need for individualized care plans and specialized nursing competencies.

In patients with chronic respiratory diseases (PAR4), the coexistence of cardiovascular, metabolic and psychiatric comorbidities reflects a multidimensional care burden. For nurses, this requires integrated management of respiratory support, monitoring of comorbid chronic diseases and attention to mental health aspects, which are often underrecognized but contribute significantly to overall care complexity and patient outcomes [11,21].

Importantly, the comparison between care settings reveals structurally different nursing demands. Patients in shared living facilities (SLF) exhibit higher overall multimorbidity, including increased prevalence of PEG use, cardiovascular disease and metabolic disorders. This indicates a higher level of clinical complexity and justifies increased staffing levels, advanced competencies and structured care processes in these settings. In contrast, patients in individual home care (IHC) more frequently present with neurological conditions such as spasticity and epilepsy, requiring specialized neurological nursing skills and

close monitoring despite a lower overall burden of systemic comorbidity.

Overall these findings demonstrate that secondary diagnoses are not merely additional clinical information but are central determinants of nursing workload, required competencies and care organization in OHIC. Systematic consideration of comorbidity patterns - particularly when structured through clinically reasonable admission groups- can support more accurate staffing models, targeted training programs and improved allocation of resources. Moreover, they provide a foundation for developing standardized care pathways that reflect the actual complexity of patients rather than relying solely on primary diagnoses or administrative classifications.

### **Integration into the German Policy Context (IPReG)**

The findings of this study are highly relevant in the context of the German “Intensivpflege- und Rehabilitationsstärkungsgesetz” (IPReG) [22], which fundamentally restructured OHIC provision since October 29<sup>th</sup> 2020.

IPReG introduced a new legal entitlement to out-of-hospital intensive care strengthened quality requirements and mandated regular assessments to ensure appropriate and needs-based care. It also explicitly aims to improve care quality and to reduce inappropriate long-term ventilation and/or tracheal cannulation.

A central objective of the reform is to align care provision more closely and to eliminate structural inefficiencies and misallocation of resources. In this context, the present findings provide important empirical support for several policy goals:

1. The demonstrated heterogeneity of patient populations highlights the need for differentiated, indication-based care allocation. The clear clustering of diagnostic groups across care settings suggests that such allocation mechanisms already exist but are not yet standardized.
2. The high incidence of multimorbidity - particularly in SLF - supports the need for quality-assured care structures and regular reassessment. The policy requirement for evaluation of care appropriateness directly corresponds to the complexity observed in this study.
3. The underestimation of key functional impairments such as dysphagia in administrative data highlights a critical challenge for the implementation of IPReG: Accurate needs assessment. Since eligibility and care planning increasingly depend on structured evaluations, reliance on incomplete coding systems may undermine the intended improvements in care quality.

Finally, the findings underscore the importance of qualified nursing staff and specialized competencies. The observed variability in

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care complexity suggests that standardized staffing ratios alone may be insufficient without incorporating patient-specific clinical profiles.

### Limitations and Strengths

Several limitations should be considered. First, some variables were derived from different data sources, which may limit comparability. Second, the cross-sectional design precludes causal inference. Third, variability in documentation practices may have influenced the reporting of secondary diagnoses.

Additionally, important factors such as functional status and social determinants were not available but are likely to play a crucial role in care allocation and outcomes.

Strengths include the large nationwide sample, physician validation of diagnostic categories, and systematic documentation of nursing-relevant parameters.

### Conclusion

This study demonstrates that OHIC is characterized by a highly complex, predominantly neurologically driven patient population with substantial multimorbidity. Significant differences between care settings in terms of age, diagnostic profile and comorbidity patterns indicate underlying structural allocation mechanisms.

By linking clinical findings with nursing practice and policy context, the results underline the need for functionally informed classification systems, differentiated care models, and evidence-based staffing approaches. These aspects are worth considering when implementing IPReG, as they provide a clearer understanding of patients' needs and the complexity of care.

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