

RESEARCH ARTICLE

Well-being on supportive techniques in amyotrophic lateral sclerosis: from neurologists' perspective

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Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease that has been increasing in incidence in recent years.^{1–3} It progressively impairs the functional independence of the patient, including mobility, speech,

Abstract

Objective: To investigate intercultural neurologists' perception of well-being in patients with amyotrophic lateral sclerosis (ALS) using gastrostomy (PEG), non-invasive, and/or invasive ventilation (NIV/IV) and to analyse the determinants and impact on the management of the above medical interventions (MIs). **Methods:** The study was based on anonymous questionnaires addressing the clinical approach and personal attitude towards the use of PEG, NIV and IV in ALS patients completed by 465 neurologists: 228 from Germany and 237 from Poland. **Results:** The German and Polish neurologists estimated the quality of life in ALS patients using PEG and NIV as neutral, whilst low in individuals using IV. A regression model revealed an independent influence of palliative care training (PCT) and age on that attitude in the German group. Higher values of estimated patients' depressiveness on PEG, NIV and IV were found amongst the Polish neurologists. Marital status, experience in ALS and being a parent independently influenced the perception of patients' depressiveness in the German, whilst marital status, age and PCT were factors in the Polish group. Amongst German neurologists, a higher perception of patients' depressiveness in individuals using PEG, NIV and IV was linked to the later timing of the MIs discussion. In the Polish group, it was a lower estimation of QoL in patients using PEG. **Conclusion:** Neurologists' perception of ALS patients' well-being on MIs reflects their demographic status, professional experience and potentially their cultural background. This perception plays an important role in the timing of MIs discussion, possibly influencing the decision-making process.

swallowing, and breathing.^{4–6} Since there is no therapy able to halt the disease progression, the supportive techniques are of great value. They include medical interventions (MIs), such as artificial feeding (percutaneous endoscopic gastrostomy, PEG) and breathing support (non-invasive or invasive ventilation, NIV or IV). If

initiated early, they can improve the quality of life (QoL) (PEG and IV) and extend the survival (PEG, NIV, IV), but none of them significantly impacts the ongoing deterioration of physical independence.^{7,8} Since life priorities and desires upon the disease outcome differ amongst patients,^{9–11} it is essential for a physician to introduce the patient to both the expected benefits and the risks/consequences of the offered intervention. Such discussions should start prior to the onset of symptoms, giving enough time for the process of informed consent, therefore, allowing for timely implementation of the measure.

In most cases, it is the neurologist who triggers the decision-making process and decides on the timing of the discussion, the amount and quality of information given to the patient, and the way of adapting the information to the patient's perception. All of these factors contribute to the final choices of patients with ALS (PALS).^{12–15} We have previously shown that depending on professional experience, neurologists caring for PALS underestimate the QoL of individuals using PEG and NIV and/or IV.¹⁶ In the current work, we hypothesise that this anticipated QoL linked to a given MI may frame a personal approach of the physician towards the management of MIs, and therefore, influences the final choices of PALS. To the best of our knowledge, no studies have yet attempted to explore such a relation in neurologists caring for PALS.

Due to differences in economic, socio-cultural and legal factors linked to particular healthcare systems, different management strategies can be expected across countries. For the purposes of this work, we compared the personal attitudes of neurologists in two neighbouring European countries, Germany and Poland. Besides the cultural background, there are important differences in national health strategies for palliative care. Germany was the first European country to implement laws concerning palliative care (1997), whilst no national palliative care plan has yet been introduced in Poland.^{17,18} The advanced directives (ADs), designed to induce earlier discussion on therapeutic choices, are regulated by the German (Bürgerliches Gesetzbuch) but not the Polish national law.¹⁹ Although the “pro futuro” statements have been decided by the Supreme Court in Poland to have legal ramifications in medical practice, they are rarely used.¹⁸ Additionally, the two countries differ in the option to terminate IV on a patient's request, being allowed in Germany, whilst defined as illegal in Poland.

The aims of the study were to (i) compare the personal perception of well-being in PALS using mechanical ventilation (NIV and IV) and/or PEG between the German and Polish neurologists, (ii) explore the determinants of the judgements and (iii) define the relationship between the individual perception of patients' well-being and the preferred management of MIs in PALS.

Methods

Data collection

A total of $N = 3015$ questionnaires were sent out by traditional or electronic mail to neurologists from all provinces in both Germany and Poland, in detail shown in Figure 1. Neurologists' names were randomly selected from available platforms (jameda.de, znanylekarz.pl). Data were collected between June 2016 and April 2019.

We received 228 completed questionnaires from the German and 237 from the Polish study population (response rates were 27% and 19%, respectively). The most common causes for returned envelopes were an invalid address or temporary absence (maternity leave, holiday break). The major reason for returning an empty questionnaire was a lack or little experience in the field of ALS.

The questionnaire regarded (i) *professional approach* towards MIs in the context of ALS (the expected patients' QoL and depressiveness on the usage of PEG, NIV, and IV; defining PEG, NIV and IV as a profitable measure for PALS); (ii) *general practice* (the timing of the MIs discussion; the attitude towards the role of the patients and their families in the decision-making process considering MIs; the role of the physician in advising about MIs); (iii) *personal approach* towards MIs (in case of hypothetical personal need for their use); (iv) *emotional distress* caused by the management of MIs.

The demographic data included *age, gender, marital status, children* and *religious beliefs*; whilst the professional experience included the *number of PALS seen per month, the number of years of experience in ALS* and completed *palliative care training (PCT)*.

Patients' well-being

Physicians were asked to estimate the QoL in PALS on the use of PEG, NIV and IV, using an adapted version of the anamnestic comparative self-assessment (ACSA), i.e. a Likert scale ranging from -5 (as bad as possible) to 5 (as good as possible).²⁰

Estimated depressiveness was assessed on a Likert scale ranging from 0 (no symptoms of depression) to 10 (severe symptoms of depression) in PALS on the use of PEG, NIV and IV.

Decision-making

To explore the patient-physician and patient-family relationship in the decision-making process, physicians were asked to choose one out of five attitudes on the adapted version of “Decision Shared Making Questionnaire” (Full details are shown in Table 1).

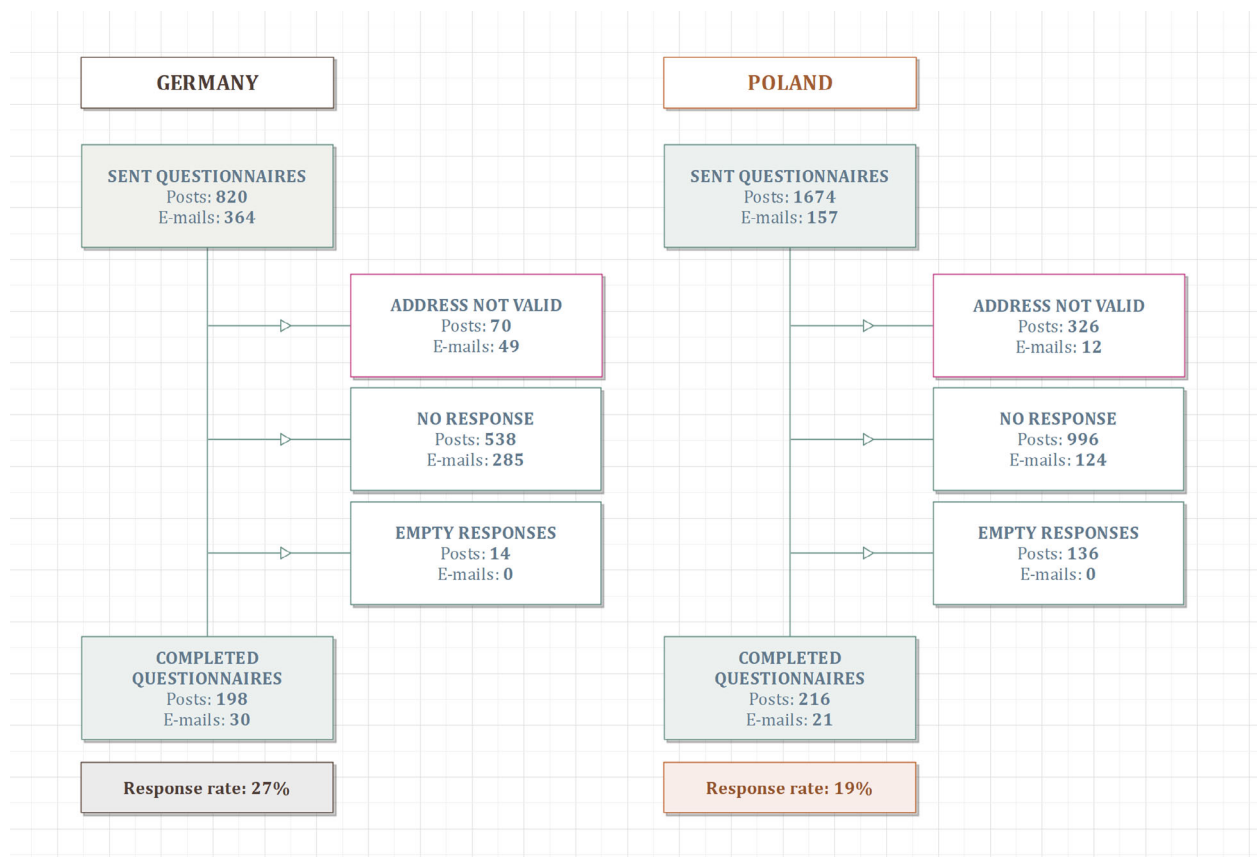


Figure 1. Data collection for the study.

Table 1. Shared Decision Questionnaire used for the evaluation of the physician/family’s role in the decision-making process.

“Decision shared questionnaire”	
1	Decision should be made solely by the physician/family
2	Decision should be made by the physician/family, but with the consideration of the patient’s opinion
3	The decision should be made equally by the physician/family and the patient
4	Decision should be made by the patient, but with the consideration of the physician/family’s opinion
5	Decision should be made solely by the patient

Statistical analysis

Chi-square and Mann–Whitney *U*-tests were used for comparisons between the countries for nominal and ordinal variables, respectively. Due to a significant difference in gender between the German and Polish neurologists, we applied two-way ANOVA to investigate differences concerning the personal perception of QoL and depressiveness with gender and nationality as independent factors. Spearman’s rank coefficient was applied to test for

significant correlations. Logistic regression was used to determine odds ratio (OR) for the rating of the impact of the QoL and depressiveness’ on the timing of the discussions considering the MIs. Multiple regression analyses were applied to detect variables affecting the reported attitudes and practises of the neurologists. We used *age*, *gender*, *marital status*, *having children*, *religious beliefs*, *PCT* and *experience rate* (ExpR), calculated as the *number of patients seen per month* × *years of experience*, as controlling variables.

Results

Physicians’ characteristics

Amongst 456 interviewed neurologists (228 from Germany and 237 from Poland), the majority had over 10 years of experience (72.63%) and would consult 1–3 PALS per month on average (78.9%). Sixteen per cent of neurologists declared taking part in scientific or clinical studies on ALS (11.9% in Poland and 19.7% in Germany). In the German group, there were more males and

individuals who completed PCT, a lower value of self-reported religiousness and a lower number of widowers compared to the Polish group (Table 2).

Well-being: personal perception

Quality of life

The median estimated QoL (eQoL) of PALS using PEG or NIV was neutral (0 and 0, respectively) and low (−2) for those settled on IV. There were no significant differences between German and Polish neurologists (Table 3).

In both countries, the higher eQoL in patients using PEG, NIV, and IV was linked to a more positive attitude

Table 2. Neurologists' characteristics.

	Entire group	German group	Polish group	p-value
Gender, %				
Male	52.86	62.74	42.79	<0.001*
Female	47.14	37.26	57.21	
Age, %				
<30	3.38	3.67	3.08	0.123
30–39	14.83	13.76	15.86	
40–49	26.97	30.28	23.79	
50–59	32.81	35.32	30.40	
60–69	17.53	14.22	20.70	
>70	4.49	2.75	6.17	
Marital status, %				
Married	85.17	87.1	83.33	0.007*
Single	19.03	8.76	5.70	
Divorced	3.60	3.23	3.95	
Widowed	4.05	0.92	7.02	
Kids, %				
Yes	83.07	80.93	85.09	0.244
No	16.93	19.07	14.91	
Religiousness, %				
Non-believing	19.41	23.15	15.86	<0.001*
Quite believing	34.09	46.3	22.47	
Believing	38.15	26.39	49.34	
Deeply believing	8.35	4.17	12.33	
How many patients seen per month, %				
<1	15.95	17.11	14.83	0.547
1–3	78.88	75.00	82.63	
4–10	34.48	5.70	1.27	
>10	1.72	2.19	1.27	
How many years of experience in ALS, %				
<1	6.04	4.82	7.20	0.542
1–5	8.62	8.77	8.47	
5–10	12.72	12.72	12.71	
>10	72.63	73.68	71.61	
Palliative care training, %				
Yes	20.26	12.28	27.97	<0.001*
No	79.74	87.72	72.03	

ALS, Amyotrophic Lateral Sclerosis.

*Statistically significant.

Table 3. Neurologists' perception of quality of life and depressiveness in patients with amyotrophic lateral sclerosis using PEG, NIV and IV.

	German group		Polish group		p-value
	Median	(Q1, Q3)	Median	(Q1, Q3)	
PEG					
QoL	0	(−1.25, 2)	0	(−2, 2)	0.103
Depressiveness	4	(3, 6)	6	(5, 8.5)	<0.001*
NIV					
QoL	0	(−2, 2)	0	(−2, 2)	0.144
Depressiveness	4	(3, 6)	7	(5, 9)	<0.001*
IV					
QoL	−2	(−3, 0)	−2	(−4, −1)	0.476
Depressiveness	6	(4, 8)	8	(7, 10)	<0.001*

QoL, quality of life; PEG, percutaneous endoscopic gastrostomy; NIV, non-invasive ventilation; IV, invasive ventilation.

*Statistically significant.

to define each of these measures as a beneficial therapeutic option for PALS (*German group*: $\rho = 0.414$, $p < 0.001$; $\rho = 0.246$, $p < 0.001$; $\rho = 0.289$, $p < 0.001$, respectively; *Polish group*: $\rho = 0.274$, $p < 0.001$; $\rho = 0.183$, $p < 0.05$; $\rho = 0.356$, $p < 0.001$, respectively). In addition, the higher eQoL on the use of PEG, NIV, and IV was related to a more favourable attitude towards the hypothetical decision to opt for each of these measures by physicians themselves (*German group*: $\rho = 0.457$, $p < 0.001$; $\rho = 0.282$, $p < 0.001$; $\rho = 0.187$, $p < 0.01$, respectively; *Polish group*: $\rho = 0.281$, $p < 0.001$; $\rho = 0.231$, $p < 0.05$; $\rho = 0.271$, $p < 0.001$, respectively).

Depressiveness

Overall, the estimated depressiveness (eDep) was of *moderate* value for patients using PEG or IV (5 and 5, respectively) and of *high* value for those using IV.⁷ The Polish group reported significantly higher values of eDep in individuals using PEG (6 vs. 4, $p < 0.001$), NIV (7 vs. 4, $p < 0.001$) and IV (8.5 vs. 6, $p < 0.001$).

We found a negative correlation between defining PEG, NIV, and IV as beneficial therapeutic options for PALS and the eDep on each of these measures in the German group ($\rho = -0.258$, $p < 0.001$; $\rho = -0.219$, $p < 0.005$; $\rho = -0.215$, $p < 0.005$, respectively). In the Polish group, a significant correlation was only related to IV ($\rho = -0.356$, $p < 0.001$). In addition, there was a significant inverse correlation between the higher eDep on the use of PEG, NIV and IV and the favourable attitude towards the hypothetical decision to opt for each of these measures by physicians themselves in the German ($\rho = -0.218$, $p < 0.005$; $\rho = -0.177$, $p < 0.05$;

$\rho = -0.173$, $p < 0.05$, respectively) and the Polish group ($\rho = -0.281$, $p < 0.001$, $\rho = -0.231$, $p < 0.05$; $\rho = -0.271$, $p < 0.001$, respectively).

Well-being: determinants

In the German group, multiple regression analyses revealed that the favourable perception of the patient's QoL was related to completed PCT ("for NIV": $\beta = 0.249$, $p < 0.001$; "for PEG": $\beta = 0.276$, $p < 0.001$) and younger age ("for NIV": $\beta = 0.167$, $p = 0.014$; "for PEG": $\beta = 0.170$, $p = 0.019$), whilst higher Expr ("for IV": $\beta = 0.150$, $p = 0.047$; "for PEG": $\beta = 0.178$, $p = 0.015$), being married/single (compared to widowed/divorced) ("for NIV": $\beta = 0.168$, $p = 0.022$), and being a parent ("for PEG": $\beta = 0.190$, $p = 0.011$) were associated with lower eDep.

In the Polish group, completed PCT ("for PEG": $\beta = 0.211$, $p = 0.007$), younger age ("for IV": $\beta = 0.181$, $p = 0.028$; "for PEG": $\beta = 0.167$, $p = 0.039$), and being widowed (compared to married/divorced) ("for PEG": $\beta = 0.160$, $p = 0.045$) were related to lower eDep.

In the entire neurologist cohort, declared participation in ALS research resulted in higher ratings of patients' QoL on NIV ($p = 0.002$), IV ($p = 0.033$), PEG ($p < 0.001$), respectively, as well as in lower ratings of patients depressiveness on NIV ($p = 0.027$), IV ($p = 0.027$), PEG ($p = 0.007$), respectively.

Management: general practice

Timing of the discussion considering the medical interventions

Amongst all physicians, 33.5% discussed the MIs at the diagnosis, 58.2% at the time of indication, and 8.3% when asked by the patient. There was a significant difference between the German and Polish neurologists regarding this practice (*at the diagnosis/at time of indication/when asked*): 53.2%/41.8%/2.5% vs. 13.1%/75.1%/11.8%, respectively ($p < 0.001$).

Multiple logistic regression analysis showed that having children (OR: 2.52, $p = 0.025$) was a determinant of an early MIs discussion in the German group, whilst younger age (OR: 1.85, $p = 0.025$) and female gender (OR: 2.63, $p = 0.044$) were linked to a later MIs discussion in the Polish group.

Shared decision-making

According to the largest group of interviewed neurologists (38.9%), the decision on therapeutic options

should be made by the patient, but considering the physician's opinion. There was no significant difference between the groups on that attitude ($p = 0.650$). In the family-patient relationship, the majority of German physicians (54.1%) declared that the family should not participate in the patient's decision-making; the most common opinion of the Polish neurologists was that the decision should be taken by a patient, but taking into consideration the family's opinion (46.9%) ($p < 0.001$) (Table 3).

Emotional distress

Most Polish neurologists (96.5%) declared that providing care for PALS caused high emotional distress. It was significantly higher than in the German group where it accounted for 78.6% ("Yes": 30.9% vs. 71.3%, "Rather yes": 47.7% vs. 25.2%, "Rather not": 19.5% vs. 1.7%, "No": 1.8% vs. 1.7% in German and Polish group, respectively, $p < 0.001$; Table 4).

Management: an impact of patients' perceived well-being

Timing of the discussion considering the medical interventions

In the German group, the odds for later discussing ("when indicated" vs. "at the diagnosis") of MIs increased by 17%, 15% and 23% for each point of a higher eDep in patients on PEG (OR: 1.17, $p = 0.027$), NIV (OR: 1.15, $p = 0.046$) and IV (OR: 1.23, $p = 0.003$), respectively. In the Polish group, the odds of earlier discussion ("at the diagnosis" vs. "when indicated") of MIs increased by 27% for each point of higher eQoL (OR: 1.27, $p = 0.019$) in patients on PEG (Table 5).

The German group had a more decisive attitude towards advising patients in the decision-making process ("Should the physician advice on therapeutic options?"), and this approach was related to the earlier discussion of MIs (OR: 1.92 [CI 95%, 1.149–3.195], $p = 0.013$). The Polish group showed a similar attitude, but it was not statistically significant (OR: 1.30 [CI 95%, 0.872–1.915], $p = 0.185$) (Table 6).

Shared decision-making

In the Polish group, there was a positive correlation between the higher eDep in patients using PEG and the attitude to leave the decision for the patient ($\rho = 0.187$, $p < 0.05$), and between the higher eQoL on NIV and the positive attitude towards advising patients in the decision-making process ($\rho = 0.198$, $p < 0.01$).

Table 4. Neurologists' perspectives on the decision-making process considering the medical interventions in patients with amyotrophic lateral sclerosis.

"Who should make the decision?"	Entire group (%)	German group (%)	Polish group (%)	p-value
Physician alone	1.1	0.5	1.8	0.650
Physician (but taking Patient's view into consideration)	8.5	6.8	10.3	
Both patient and physician	26.1	30.8	21.4	
Patient (but taking Physician's view into consideration)	38.9	37.6	40.2	
Patient alone	25.40	24.4	26.3	
Family alone	0.7	0.5	0.9	<0.001*
Family (but taking Patient's view into consideration)	4.7	2.3	7.0	
Both patient and family	9.6	11.8	7.5	
Patient (but taking Family's view into consideration)	39.3	31.4	46.9	
Patient alone	45.8	54.1	37.7	

*Statistically significant.

Table 5. Logistic regression analyses for the timing of medical interventions' discussion in view of quality of life and depressiveness.

At the diagnosis (vs. when indicated)			
Variable	OR	95% CI	p-value
German group			
PEG			
QoL	1.092	(0.965, 1.237)	0.160
Depression	0.855	(0.745, 0.982)	0.027*
NIV			
QoL	1.133	(0.998, 1.286)	0.053
Depression	0.868	(0.755, 0.998)	0.046*
IV			
QoL	1.075	(0.946, 1.222)	0.265
Depression	0.812	(0.708, 0.932)	0.003*
Polish group			
PEG			
QoL	1.271	(1.041, 1.553)	0.019*
Depression	0.920	(0.771, 1.098)	0.357
NIV			
QoL	1.048	(0.865, 1.268)	0.635
Depression	1.071	(0.895, 1.281)	0.455
IV			
QoL	1.046	(0.875, 1.251)	0.620
Depression	1.005	(0.822, 1.228)	0.963

OR, odds ratio; CI, confidence interval; PEG, percutaneous endoscopic gastrostomy; NIV, non-invasive ventilation; IV, invasive ventilation.

*Statistically significant.

Emotional distress

Emotional distress imposed by the provided care for PALS was found to be significantly related to the eQoL and eDep on PEG ($\rho = -0.200$, $p < 0.001$ and $\rho = 0.289$, $p < 0.001$, respectively), NIV (only for depressiveness: $\rho = 0.209$, $p = 0.022$), and IV ($\rho = -0.160$, $p = 0.022$ and $\rho = 0.248$, $p < 0.001$, respectively) in the German group. Of note, no such relationship was found for the Polish group.

Table 6. Advising on therapeutic options to ALS patients: neurologists' view.

	German group		Polish group	
	"When do you discuss MIs?"			
"Should physicians advise on MIs?"	At the diagnosis	At later stages	At the diagnosis	At later stages
No, %	0	0	14.8	27.8
Rather no, %	1.9	7.4	25.9	24.1
Rather yes, %	36.4	46.9	33.3	29.7
Yes, %	64.1	45.7	25.9	19.0
p-value	0.017*		0.186	

MIs, medical interventions.

*Statistically significant.

DISCUSSION

Decision-making is an essential component of patient-centred healthcare and has a pivotal role in achieving satisfactory compliance to treatment. In addition to the patient- and caregiver-dependent factors,^{21–23} regular interactions with the physicians are likely to influence the decision-making process.

Well-being perception in neurologists

The neurologists interviewed in our study, independently of the country of origin, perceived the QoL as low in PALS using IV and neutral in the case of PEG or NIV. The estimated depressiveness, ranging from moderate to high degree, was found to be higher in the Polish group. This general attitude of the physicians does not mirror the widely reported maintenance of good QoL in PALS following the start of PEG or NIV.⁷ Notably, in a recent study of PALS in a locked-in state ($n = 17$ on IV, $n = 2$ on NIV), most interviewed individuals reported a positive

QoL and no signs of depression.²¹ Interestingly, PALS exhibit a so-called *well-being paradox* showing no correlation between the functional disability and the QoL or the prevalence of depression symptoms.^{21,24,25} There is even evidence that the risk of depression decreases at the later stages of the disease,²⁶ as a part of the coping process or the loss of neuronal populations responsible for emotional responses.²⁷

The discrepancy between patients' self-reported QoL and the QoL perceived by the neurologists is in line with previous studies of our and other groups. They showed that both healthy persons and caregivers of ALS patients significantly overestimated depressiveness and underestimated QoL of PALS.^{21,27-29} This phenomenon was also found amongst physicians whose correct perception of a patient's psychological status depended on their years of experience.¹⁶ Moreover, individuals with a higher depression rate and/or lower QoL perceived the well-being of others as significantly lower, most likely through the prism of their own mental state, as has been shown before.³⁰ A higher estimation of depressiveness and lower QoL may reflect this phenomenon due to significant population-based differences between Poland and Germany.²²

The attitude of the neurologist is of particular importance because the expected outcome of the proffered MI is a significant determinant of the decision-making process in ALS.³¹ In particular, the decision to opt for mechanical ventilation is based on its potential role in improving QoL (particularly in NIV) and sustaining life (both in NIV and IV), whilst opting against mechanical ventilation is driven by the estimated lack of positive effects on QoL (IV) and the burden imposed on caregivers (both in NIV and IV).^{7,32,33}

To investigate the background of neurologists' judgments in more detail, we applied the multiple regression model with physicians' demographic or professional factors as independent variables for the estimated well-being in PALS on the use of MIs. We found that PCT resulted in a significantly higher estimation of QoL on the use of NIV and PEG, being presumably more consistent with patients' self-reported values.¹⁶ The fact that it was only observed in the German population is most probably due to different training systems in the two countries. PTC in Germany is an undergraduate training secured by the German Medical Association, whilst in Poland, it is provided in the form of short (1 week) post-graduate courses. We also noted a lower eDep on the use of IV and PEG in German neurologists with a higher experience in ALS (ExR). Higher ratings of eQoL and lower ratings of eDep were also found amongst physicians taking part in ALS research compared to those who have never participated in such studies. These findings are consistent

with previous reports.³³ Thus, the quality and amount of knowledge have an influence on the physician's approach towards MIs.

Management of medical interventions: general practise

In our cohort, German neurologists discussed MIs significantly earlier with PALS than Polish neurologists. This discrepancy partially results from ADs (obligatory to be followed in Germany; not regulated by law in Poland). Supported by the recent literature, ADs can be of invaluable help in the terminal stage of the disease,³⁴ but they also bring some concerns. The primary issue involves a patient's potential changes in preference over time which is why a dynamic adaptation of ADs is suggested. In the field of ALS, an increase in MIs acceptance was reported over the first year after the diagnosis,³⁵ but since multiple studies found no correlation between the degree of disability and the well-being of the patient, no significant decline but rather an increase in a desire for supportive techniques can be expected in further stages of disease progression.^{13,33,36} In the Polish group, demographic factors resulting in earlier timing of MIs discussion were male gender, older age and favourable attitude towards advising on therapeutic options. This shows that a physician's confident attitude may have an important role in the decision-making process since the initiation of discussions considering intervention-related measures can be challenging for some physicians.³⁷ In the German population, having children was linked to the earlier discussion of MIs. This gives evidence for different determinants of management strategies across countries.

Management of medical interventions: a role of perceived well-being

In a study considering chronically ill elderly patients, the patients' QoL estimated by physicians significantly correlated with the physicians' preferences for ventilation.³⁸ The physicians reported that QoL needed to be considered when selecting the treatment.³⁹ In our cohort, the perceived well-being of patients using PEG, NIV, and/or IV was found to interact significantly with the timing of MIs discussions. In particular, initiating the MIs discussions with PALS later in the course of the disease was associated with higher estimations of depressiveness in individuals using PEG, NIV, and/or NIV in the German population. Amongst Polish neurologists, such a relationship concerning QoL was found about PEG. Further, the perception of patients' well-being on PEG, NIV, and/or IV was related to defining each measure as profitable for PALS, as well as to a hypothetical decision to opt for the

measure by the neurologists themselves. To our knowledge, this is the first study to show such interplay in ALS. The anticipated well-being of the individual after the introduction of an offered measure plays an important role in the management of MIs by neurologists, including the timing of the discussion and possibly the content of provided information.

The majority of PALS want their proxies and the physician to participate in the decision-making process; however, patient's desire for physician shared-decision-making decreases with disease duration,^{40,41} reflecting the patient's increased wish for autonomy. In our cohort, the vast majority of neurologists supported patients' autonomy in making therapeutic decisions, but in the Polish group, this attitude was additionally associated with physicians' perceived well-being of the patients. It emphasises the influence of neurologists' perspectives on patients' management.

Limitations

A potential limitation of this study is its relatively low response rate despite the large number of neurologists targeted for the survey. The physicians with little experience in ALS were most likely to less willing to complete the questionnaire. Thus, our findings may not apply to the general population of neurologists in a given country, but more to those with experience in the field of ALS. Yet, the response rate is in the expected range of many anonymous questionnaire studies,⁴² which allow no reminder to increase the response rate. Second, our study did not provide a concurrent assessment of QoL and depressiveness in PALS taken care by the respective neurologists. The real-life data from PALS in the same period described in the cited publications were obtained in specialised ALS centres, which might have influenced the patients' overall well-being.

Conclusion

The German and Polish neurologists similarly perceived the QoL as low in patients using IV and neutral in those with PEG and NIV. The levels of patients' estimated depressiveness on MIs were rated with greater intensity by the Polish neurologists. These estimations reflected the professional (experience in ALS, completed PCT) and demographic background (marital status, being a parent) of the physicians. Of major importance, the perceived well-being played a role in defining each measure as profitable for the patients and the reported management approaches, especially when it comes to the timing of the MIs discussion.

A thorough understanding of the bases of physicians' attitudes towards MIs may therefore influence the patients' decision process considering advanced treatment in ALS.

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Conflicts of Interest

None to declare.

Author Contributions

Krzysztof Barć: conceptualisation (equal), data curation (lead), formal analysis (lead), investigation (equal), methodology (equal), writing—original draft (lead), writing—review and editing (lead). Dorothee Lulé: conceptualisation (equal), data curation (equal), funding acquisition (lead), methodology (equal), project administration (equal), supervision (lead), writing—review and editing (equal). Julia Finsel: investigation (supporting), resources (supporting), writing—review and editing (supporting). Olga Helczyk: investigation (supporting), resources (supporting), writing—review and editing (equal). Susanne Baader: investigation (supporting), resources (supporting), writing—review and editing (equal). Helena Aho-Oezhan: investigation (equal), resources (equal), writing—review and editing (equal). Albert C Ludolph: project administration (equal), supervision (equal), validation (equal), writing—review and editing (equal). Magdalena Kuźma-Kozakiewicz: conceptualisation (equal), funding acquisition (lead), investigation (equal), methodology (equal), project administration (lead), resources (lead), supervision (lead), validation (equal), writing—original draft (equal), writing—review and editing (equal).

Informed Consent

Each participant was informed of the purpose of the study and gave anonymous informed consent of participation before filling in the questionnaire.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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