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Surrogate decision-making for people with disorders of consciousness: considering the control-preferences of informal caregivers before implementing multimodal testing

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Abstract

Background Historically, individuals with disorders of consciousness (DoC) have often been subject to prognostic pessimism and therapeutic nihilism, leading to clinical decisions that became self-fulfilling prophecies. Recent advances in neurodiagnostics -particularly multimodal assessments of consciousness- offer new opportunities to reduce diagnostic ambiguity and to potentially improve rehabilitation outcomes. These developments have the potential to support more effective care planning. Given their central role in surrogate decision-making, informal caregivers are increasingly recognised as key participants in this evolving process. Yet, little is known about the distribution of their preferred roles in decision-making, especially in light of emerging, technology-informed models of diagnosis. Two research questions guided a multicenter study within the PerBrain project: (1) To what extent do informal caregivers differ in their preferences regarding control over decision-making and (2) does a majority of informal caregivers prefer a collaborative model over other forms of decision-making?

Methods A cross-sectional survey using a modified version of the Control Preferences Scale (CPS) -which measures a person's preferred level of control in medical decision-making- was conducted with informal caregivers of persons with DoC in three medical units in Italy and Germany between March 2021 and June 2023. The participating medical centers were part of the PerBrain project, which investigates multimodal consciousness assessment. Caregivers were recruited consecutively, and data were analysed using descriptive statistics, chi-square tests, and t-tests to assess cross-national differences.

Results Seventy caregivers completed the survey. Preferences regarding decision-making roles varied: 34 (48.6%) favoured a passive role, 26 (37.1%) preferred a shared or collaborative role, and 10 (14.3%) expressed a preference for an active role. When ranked across all six possible positions (from active to passive options), the collaborative approach was most frequently among the top three choices: 26 (37.1%) ranked it first, 20 (28.6%) second, and 19

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(27.1%) third. Statistically significant cross-country differences emerged ($\chi^2(2) = 7.408$, $p = .025$), with German caregivers demonstrating a stronger preference for active participation than their Italian counterparts.

Conclusion Healthcare professionals should be attentive to the diversity of decision-making preferences expressed by family caregivers of patients with DoC shortly after the transition from intensive to rehabilitation care. Although SDM is widely regarded as the normative standard in clinical practice, our findings reveal a discrepancy between this standard and the actual preferences of informal caregivers in two similar care settings in two different European countries. The findings add to the literature on uncertainty in surrogate health-care decision-making for people with DoC and raise questions of whether SDM should even be implemented, when it is not the preferred approach of (future) surrogate decision-makers.

Trial registration The study protocol was registered at ClinicalTrials.gov (identifier: NCT04798456). The study was retrospectively registered on 15 March 2021 for the purpose of transparency. The protocol had been finalized before the start of the data collection. Further details can be accessed at https://clinicaltrials.gov/ct2/show/NCT04798456.

Keywords Neurological Rehabilitation [MeSH], Caregivers [MeSH], Decision Making, Shared [MeSH], Consciousness Disorders [MeSH], Persistent Vegetative State [MeSH], Unconsciousness [MeSH], Neurological Rehabilitation [MeSH]

Introduction

Advances in medical care have considerably improved the survival rates of individuals with severe brain injuries, but not all survivors recover to the extent that they regain the ability to meaningfully interact with their environment or with others [1]. A study estimates that approximately 20–40% of patients, who survive severe acquired brain injuries, are diagnosed with disorders of consciousness (DoC) [2]. DoC is an umbrella term for three syndromes: coma, the unresponsive wakefulness syndrome (UWS), previously known as vegetative state (VS), and the minimally conscious state (MCS) [3]. DoC vary in the extent of wakefulness and awareness, ranging from coma (no wakefulness) [4] to UWS (open eyes without signs of awareness) to the MCS (fluctuating but minimal signs of awareness). The latter is further distinguished into MCS+ (showing higher-level behaviors such as command following or basic communication) and MCS– (limited to lower-level responses) [5]. Some patients may even retain covert awareness, known as cognitive motor dissociation, detectable only with specific neuroimaging or electrophysiological techniques. The current nosology shows that DoC is an umbrella term for a variety of syndromes that differ from one another in terms of capabilities of patients, their care needs and most importantly with regard to the prognosis. The conditions can be transient or chronic, yet the criteria for defining chronicity remain debated due to limited evidence [6]. It has been questioned to rely on certain time frames when to assume that a DoC has become chronic based on the thin evidence-base of such assumptions [7]. In the past, persons with DoC have often faced prognostic pessimism and therapeutic nihilism, leading to self-fulfilling prophecies [8]. This general assumption is currently changing, especially because it has been shown that persons with MCS are expected to have a better prognosis than persons with UWS [9].

The differential diagnosis of DoC has been difficult to make, with a high rate of misdiagnosis of approximately 40% [5]. The development of innovative health technologies could be promising for improving the diagnostic accuracy and decreasing diagnostic uncertainty. A novel approach for multimodal diagnostic testing of the ability for consciousness in DoC has been tested in the project PerBrain [10]. The project aims at decreasing the uncertainty accompanying diagnosis and prognosis for people with DoC by integrating multimodal data into a personalised hierarchical procedure. The test-battery incorporates multiple behavioural, clinical, and neurodiagnostic assessments according to a patient-tailored multi-layer workflow. In line with recommendations by the European Academy of Neurology, techniques include well-established behavioural scales, neurophysiological techniques, including (functional) electroencephalography and transcranial magnetic stimulation, functional magnetic resonance imaging, fluorodeoxyglucose positron emission tomography, and measurements of physiological activity, such as respiratory activity [11]. Findings of such test-batteries are then integrated based on an evaluation by experts and can furthermore be processed through algorithmic procedures which can be used e.g., for the purpose of treatment outcome prediction. In this manuscript we refer to the usage of such technological measures in health-care decision-making about a patient's diagnosis, prognosis and treatment more broadly as a form of *technology-informed health care decisions*. In previous studies, approaches of multimodal testing have been successful in improving diagnosis and prognosis in clinical unresponsive critical-care patients with brain injury [12, 13]. This effect has the potential to change the way certain patients are being cared for and treated, including decision-making about the goals of health care. Accompanying studies which start data-collection before diagnostic innovations are being introduced to the informal caregivers of patients could reveal important insights in the conditions for such processes. Hence, our study can provide a lay of the land against which changes can be observed in such study contexts.

In exploring new diagnostic approaches, it is important to consider not only their impact on individuals with DoC, but also on others involved in their care and treatment decisions. By definition, patients with DoC are not competent to make health decisions, yet it remains a matter of debate who should make these value-laden decisions on behalf of the patient and how such decisions should be approached [14, 15]. Unlike many other conditions in which patients require surrogate decision-making (e.g., delirium, mental disorders, advanced dementia), individuals with DoC present a qualitatively unique challenge. Due to severe disturbances of consciousness that lead to an inability to communicate their preferences, they are completely incapable of making decisions, while at the same time the diagnostic and prognostic uncertainty is exceptionally high. Diagnostic errors (e.g., mistaking MCS for UWS) can have far-reaching implications for decision-making about the goals of care. Furthermore, the possibility of cognitive motor dissociation increases the possibility that signs of covert awareness might have been previously overlooked.

In most Western countries, surrogate decision-making should not only be informed by the diagnosis and prognosis of the rehabilitation treatment but also by advance directives or the person with DoC's known or presumed treatment preferences in similar clinical situations [15] . Still, surrogate decision-making for people with DoC involves significant uncertainty, stemming from scientific, practical, personal, and ethical factors [16]. In the face of such uncertainties, shared decision-making (SDM) has been increasingly proposed as a suitable approach for surrogate decision-making [17, 18], aiming to balance medical expertise with the values and preferences of the patient and their family. SDM is widely recognised as a term for a collaborative structured process where patients and healthcare providers work together to make decisions that align with the patient's values, preferences, and the best available clinical evidence [19]. It has been applied to surrogate decision-making with the adaptation that a surrogate should not base their decisions on their own preferences but on the patient's preferences and wellbeing [20]. There is no singular, universally accepted model for applying SDM, as its implementation can vary depending on several factors, such as the clinical context, the individuals involved, and the specific healthcare setting [21]. Despite the increasing endorsement of SDM by researchers as an ethically justified approach to decision-making, it remains unclear (1) how decision-making preferences of informal caregivers involved in the care of persons with DoC are distributed, and (2) how their preferences should be taken into account, when approaching technology-informed health care decisions.

This article aims to explore the role-preferences of caregivers when involved in health care decision making for people with DoC at the start of early neurorehabilitation. Then it discusses the possible interactions between such role preferences and an implementation of multimodal testing of consciousness in early rehabilitation care. In particular, the study investigated for the first time in the context of neurorehabilitation for patients after acquired brain injury the following questions: (1) to what extent do caregivers of patients with DoC differ in their preferences regarding control over decision-making and (2) does a majority of caregivers prefer a collaborative model over other forms of decision-making?

Material and method

The reporting of the method section is oriented at the STROBE reporting checklist for cross-sectional studies [22].

Context of the study

This study was part of the caregiver sub-project of the multicenter project PerBrain (ERA PerMed JTC2019), which was mainly focused on the development of a multimodal hierarchical approach to personalised tracking of evolving state-of-consciousness in brain injured patients [10]. The project took place in four countries (France, Italy, Germany, Israel), of which three participated in the caregiver-subproject (France, Italy, Germany), yet this study-part was only fully implemented in Italy and Germany.

Among its objectives, the caregiver sub-project addressed the ethical and social implications of the new health technology developed within the PerBrain project. Informal caregivers were invited to participate in the study after giving their written informed consent. The consecutive sampling and recruitment of the sample took place at three sites in two countries: Italy/Milano (IRCCS Santa Maria Nascente Fondazione Don Carlo Gnocchi ONLUS), Germany/Burgau (Hospital for Neurorehabilitation/Therapiezentrum Burgau) and Germany/Munich (University Hospital of Munich /Klinikum der Universität München, KUM, Ludwig-Maximilians-Universität, LMU). The two rehabilitation facilities where this study took place are the IRCCS Fondazione Don Carlo Gnocchi of Milan, part of a non-profit foundation specialised in neurorehabilitation, that operates nationally within the Italian public healthcare system, and Therapiezentrum Burgau, a specialised hospital for neurorehabilitation within the German public healthcare system.

In Italy, the neurorehabilitation facility has 40 beds for patients with severe acquired brain injury. Patients may remain for up to 6 months, and approximately 10–15%

of admissions involve individuals with DoC. In Germany, the neurorehabilitation facility has 111 beds, of which around 10% are for patients with a DoC diagnosis. The average length of stay during early neurorehabilitation is approximately 60 days.

Both institutions represent exemplary post-acute neurorehabilitation centres in their respective countries, that are similar but also different from other centres. Compared to other early rehabilitation settings in Italy and Germany, they are similar with regard to the targeted patient populations. What distinguishes them from most centres is their focus on neuroscientific research and therefore also their early implementation of multimodal testing in the diagnostic process. Hence, our sample can be considered broadly reflective of caregivers of patients with DoC in highly specialized rehabilitation contexts, but also might include cases that were directed to these centres because of their specialisation. Moreover, we did not systematically collect data on non-participants, which limits direct comparisons between participants and those who declined.

Research ethics approval

The study was conducted in compliance with the ethical standards in the WMA-Declaration of Helsinki (2013) [23]. Ethics approval for the study was granted in both countries accordingly. by the Institutional Review Boards at the Medical Faculty of LMU Munich/Germany (protocol number 20–634 and 20–635) and at the Comitato Etico IRCCS “Fondazione Don Carlo Gnocchi” of ethics committee IRCCS Regione Lombardia/Italy (protocol number 32/2021/CE_FdG/FC/SA). Potential participants were identified and approached by the responsible physician (AC or AB), in collaboration with the data acquisition team (MR, LW, CV, PO), and all of the involved researchers supported the process of study explanation and informed consent, when needed. Participants gave their written informed consent and their data was pseudonymized to ensure the protection of privacy.

Study design

Data was mostly gathered at T0 at the patient’s admission to the rehabilitation hospital. A small number of patients and informal caregivers were recruited at the acute hospital of the University Hospital Munich (KUM) up to one week prior to admission and subsequently transferred to the rehabilitation facility (Therapiezentrum Burgau). The process between recruitment and transfer has taken up to a week. This means that for this subgroup, parts of the data collection took place in an acute care facility, prior to admission to the rehabilitation center.

Questionnaire design

To examine caregivers’ preferences in decision-making for their loved ones, we adapted the Control Preferences Scale (CPS) [24] to match the context of surrogate decision-making for people with DoC. The CPS itself is a validated and frequently applied instrument in treatment decision-making research [25, 26]. Originally, the CPS comprises five cards, each depicting a distinct role in treatment decision-making through a brief statement and a cartoon illustration. These roles range from the patient making all treatment decisions independently, to collaborative decision-making with the physician, to the physician making the decisions alone. The collaborative decision-making style aligns closely with the concept of SDM, which entails joint responsibility and mutual control over healthcare decisions between clinicians and patients—or, in this case, their surrogates [18, 27]. The original CPS has been translated and validated both into Italian and German [28] [29].

A multidisciplinary group of experts in Italy and Germany (including researchers, physicians, psychologists, and a bioethicist) collaboratively translated and back-translated the modified CPS, discussed wording changes and the addition of a new item, and ensured comprehensibility through pilot testing with caregivers. Consistent with previous adaptations of the CPS [27], we started from the original scale but modified it to better reflect the potential preferences of informal caregivers of patients with DoC (see Supplementary Material 1). To make it easier to apply in the three study contexts, we changed the measurement model from unfolding theory (where cards had to be compared subsequently) to self-administered survey. The wording of the items was adjusted to reflect the caregivers’ possible role as surrogate decision-makers for people with DoC. Moreover, to account for the potential influence of caregivers’ projection bias [29, 30], we introduced an additional item within the (ACTIVE) category. This item specifically addresses the possibility that caregivers might prefer to prioritise their own preferences when making decisions on behalf of their loved one. The new item reads: “I take decisions for my beloved one on my own, after having considered my own wishes (ACTIVE).” By explicitly including this option, we aimed to better capture the complex interplay between surrogate decision-making and personal values, thus providing a more nuanced understanding of caregiver decision-making processes [30, 31]. There are two possible strategies for analysing the questionnaire data: (1) grouping responses into the three overarching roles—passive, active, and collaborative—and assessing their overall prevalence, (2) examining how often each specific single role was chosen and the rank assigned to each role.

To complement the scale, we included a further question inspired by the questionnaire in a prior study on decision-making preferences of surrogate decision-makers for people with DoC [32]. It was focused on the actual decision-making experiences of the participants. Caregivers were asked to rate the frequency with which they engaged in each of the six decision-related behaviours described in the main questionnaire. Using a 4-point Likert scale (1 = "I usually don't do this at all" to 4 = "I usually do this a lot"), they evaluated how often they performed each behaviour in practice (see Supplementary Material 2). All questions and answers were constructed in English and translated in German and Italian using backward-forward translation by Italian and German native speakers.

Participants

The inclusion and exclusion criteria for this study were defined to ensure the selection of appropriate participants, following the CONSORT diagram for participant flow (see Supplementary Material 3). The inclusion criteria were: participants had to be an adult (> 17 years old) and informal caregivers of persons with DoC (i.e., those emotionally close to the person with DoC who provide non-professional care). Participants had to be competent to give informed consent to study participation (see ethics approval). They had to be caregivers of persons with DoC at the time of admission to the health care facility, yet it was not necessary to be legally appointed as the person's surrogate decision-maker.

Data acquisition

We recruited the sample between March 2021 and June 2023. Informal caregivers were surveyed before multimodal assessment of their loved ones. Descriptive data of the sample of participants was acquired together with the decision-preference questionnaire and other instruments [10]. To mitigate potential biases in this study, several measures were implemented. Recruitment was based on consecutive sampling to enhance sample diversity and reduce selection bias. To address response bias, caregivers were informed that there were no right or wrong answers and were encouraged to provide responses that genuinely reflected their preferences. Non-response bias was reduced by providing support by members of the study team (mostly a psychologist or MD-student) to help with questionnaire completion, reducing potential misunderstandings and ensuring participant engagement. This was only the case, if participants needed additional clarifications to understand the questions. Study team members aimed at providing neutral guidance without influencing the answers, and at the same time tried to ensure complete responses to the questionnaires.

Data analysis

Descriptive statistics (frequencies and percentages, mean, SD) were used for the analysis of the demographic and clinical characteristics of both informal caregivers and patients. We calculated confidence intervals for the proportions of decision control preferences using a multinomial distribution. Furthermore, Fisher's exact test was used to examine cross-country differences between the research participants in Germany and Italy, as it is more appropriate than parametric testing when expected cell counts are less than 5. In addition to the primary analyses, supplementary statistical tests including the *t*-test for continuous variables and the chi-square test for categorical variables were performed to explore potential associations between decision-making style and various demographic and clinical variables, such as the caregivers' legal relationship, patients' duration of rehabilitation, and diagnosis. Data were analyzed using SPSS version 29.0.

Results

Sample description

The description of the entire sample and the subsamples (Italy and Germany) is displayed in Table 1. It comprised 70 caregivers, with 33 from Italy (47.1%) and 37 from Germany (52.8%). Caregivers had a mean age of 51 years (SD = 12.63), with the majority being women ($n = 46$; 65.7%). Average level of education was 12.41 years (SD = 4.05). In terms of civil status, 55 caregivers (78.6%) were married or cohabiting, and an equal percentage had children. Most caregivers were employed, with a permanent employment (stable employment) being the most prevalent occupational status ($n = 34$; 48.6%). The majority ($n = 58$; 82.4%) reported economic independence from the patient. Regarding the relationship with patients, 29 caregivers (41.4%) were the patient's partners, 14 (20%) were parents and 11 (15.7%) were an adult son or daughter. Most caregivers ($n = 54$; 77.1%) held legal guardianship, with a significant difference between countries: 35 of 37 (94.6%) in Germany vs. 19 of 33 (57.6%) in Italy ($\chi^2(2) = 38.47$, $p < .001$). No other significant difference was detected across subsamples.

The descriptive data of persons with DoC are displayed in Table 2. Patients had a mean age of 52.37 years (SD = 17.41), and 31 patients (44.3%) were women. The primary acquired brain injury etiologies included traumatic brain injury ($n = 24$; 34.3%), intracerebral or subarachnoid hemorrhage ($n = 24$; 34.3%), and hypoxic-ischemic encephalopathy following cardiac arrest ($n = 21$; 30%). At caregivers' survey administration the mean time from patients' injury was 86.81 days (SD = 57.65), and the mean duration of stay in the facilities was 42.10 days (SD = 28.55).

Table 1 Demographic characteristics of caregiving participants

Characteristic	Total Sample (*N* = 70)	Italy (*N* = 33)	Germany (*N* = 37)
Age (Mean ± SD)	51 (12.63)	50.88 (13.52)	52.70 (11.91)
Gender (Women, *n*, %)	46 (65.7%)	23 (69.7%)	23 (62.2%)
Education (years, M ± SD)	12.41 (4.05)	12.85 (3.91)	12.00 (4.20)
Occupation (n, %)			
Fixed-term dependent employment	7 (10.0%)	4 (12.1%)	3 (8.1%)
Permanent dependent employment	34 (48.6%)	14 (42.4%)	20 (54.1%)
Occasional collaboration	2 (2.9%)	0	2 (5.4%)
Freelance/business people	3 (4.3%)	0	3 (8.1%)
Self-employment	4 (5.7%)	3 (9.1%)	1 (2.7%)
Homemaker	4 (5.7%)	4 (12.1%)	0
Student	1 (1.4%)	0	1 (2.7%)
Retired	12 (17.1%)	6 (18.2%)	6 (16.2%)
Unemployed	3 (4.3%)	2 (6.1%)	1 (2.7%)
Economic independence from the patient (n, %)	56 (82.4%)	28 (84.8%)	28 (75.7%)
Civil Status (n, %)			
Single	8 (11.4%)	6 (18.2%)	2 (5.4%)
Married or cohabiting	55 (78.6%)	22 (66.7%)	32 (86.5%)
Separated/divorced	6 (8.6%)	4 (12.1%)	1 (2.7%)
Widowed	1 (1.4%)	1 (3.0%)	2 (5.4%)
Children (n, %)	55 (78.6%)	26 (78.8%)	29 (78.4%)
Relationship to Patient (n, %)			
Partner (Cohabiting with the patient)	29 (41.4%)	12 (36.4%)	17 (45.9%)
Child	11 (15.7%)	5 (15.2%)	6 (16.2%)
Sibling	10 (14.3%)	7 (21.2%)	3 (8.1%)
Parent	14 (20.0%)	7 (21.2%)	7 (21.2%)
Other (e.g., Aunt)	3 (4.3%)	2 (6.1%)	1 (3.0%)
Legal Status (n, %)			
Legal guardian	54 (77.1%)	19 (57.6%)	35 (94.6%)
None	16 (22.9%)	14 (42.4%)	2 (5.4%)

Table 2 Demographic and clinical characteristics of patients

	Total Sample (*N* = 70)	Italy (*N* = 33)	Germany (*N* = 37)
Age (Mean ± SD)	52.37 (17.41)	49.60(18.48)	54.83 (16.24)
Gender (Women) (*n*, %)	31 (44.3%)	15 (45.5%)	16 (43.2%)
Type of Brain Injury (n, %)			
Traumatic Brain Injury	24 (34.3%)	17 (51.5%)	7 (18.9%)
Intracerabral Hemorrhage-Subarachnoid Hemorrhage	24 (34.3%)	8 (24.2%)	16 (43.2%)
Anoxia-Cardiac Arrest	21 (30%)	8 (24.2%)	13 (35.1%)
Other (Aspiration Pneumonia)	1 (1.4%)	0	1 (2.7%)
Time Between Injury and Caregivers' Assessment (days, M ± SD)	86.81 (57.65)	88.75 (64.47)	85.08 (51.66)
Time in Present Facility at Caregivers' Assessment (days, M ± SD)	42.10 (28.55)	34.48 (31.32)	48.89 (24.29)
Diagnosis (n, %)			
UWS	40 (57.1%)	18 (54.5%)	22 (59.5%)
MCS-	11 (15.7%)	6 (18.2%)	5 (13.5%)
MCS+	13 (18.6%)	9 (27.3%)	4 (10.8%)
Emergence from MCS	6 (8.6%)	-	6 (16.2%)

A significant difference in the duration of rehabilitation between the German and Italian groups was detected. The duration (in days) is significantly longer in Germany (M = 48.89, SD = 24.29) than in Italy (M = 34.48, SD = 31.32), $t(68) = -2.16$, $p = .017$.

In terms of clinical status, 40 patients (57.1%) were diagnosed with UWS, 11 (15.7%) with MCS-, 13 (18.6%) with MCS+, and 6 (8.6%) had emerged from the MCS at admission. Notably, the latter was only reported among German patients $\chi^2(3) = 8.21$, $p = .042$.

Role-preferences for decision-making

As shown in Fig. 1, most participants (*n* = 34; 48.6%) preferred a passive decision-making style the most, followed by a preference for a collaborative style (*n* = 26; 37.1%), and an active style being the least preferred (*n* = 10; 14.3%). In particular, among those with a predominant preference for a passive style (*n* = 34), 25 (73.5%) reported mainly preferring to comply with doctors' recommendations, while 9 (26.5%) preferred informing doctors of their loved one's wishes, allowing doctors to consider these when making treatment recommendations. Among caregivers who preferred an active style (*n* = 10), 5 (50%) preferred to make decisions independently after gathering information about available treatment options from doctors, 3 (30%) based their decisions on the patient's wishes, and 2 (20%) preferred to make decisions based on their personal preferences.

The preference for a collaborative role was ranked from first to sixth position (Fig. 2). A slight majority of participants (*n* = 26; 37.1%) ranked this option at the first position, followed by second position (*n* = 20; 28.6%), third position (*n* = 19; 27.1%), fourth position (*n* = 2; 2.9%), and fifth position (*n* = 3; 4.3%).

Significant cross-country differences were identified in decision-making preferences ($\chi^2(2) = 7.408$, $p = .025$) (Fig. 3), with a higher proportion of caregivers in Germany selecting an active decision-making style as their first preference. Conversely, caregivers in Italy more often preferred a passive approach. This was confirmed by Fisher's Exact Test ($p = .022$), which indicated significant differences between the two countries in terms of preferred decision-making style. Specifically, 9 of 37 (24.32%) participants in Germany favored an active approach compared to 1 of 33 (3.03%) in Italy. Conversely, 20 of 33 (60.61%) Italian caregivers preferred a passive approach, compared to 14 of 37 (37.84%) in

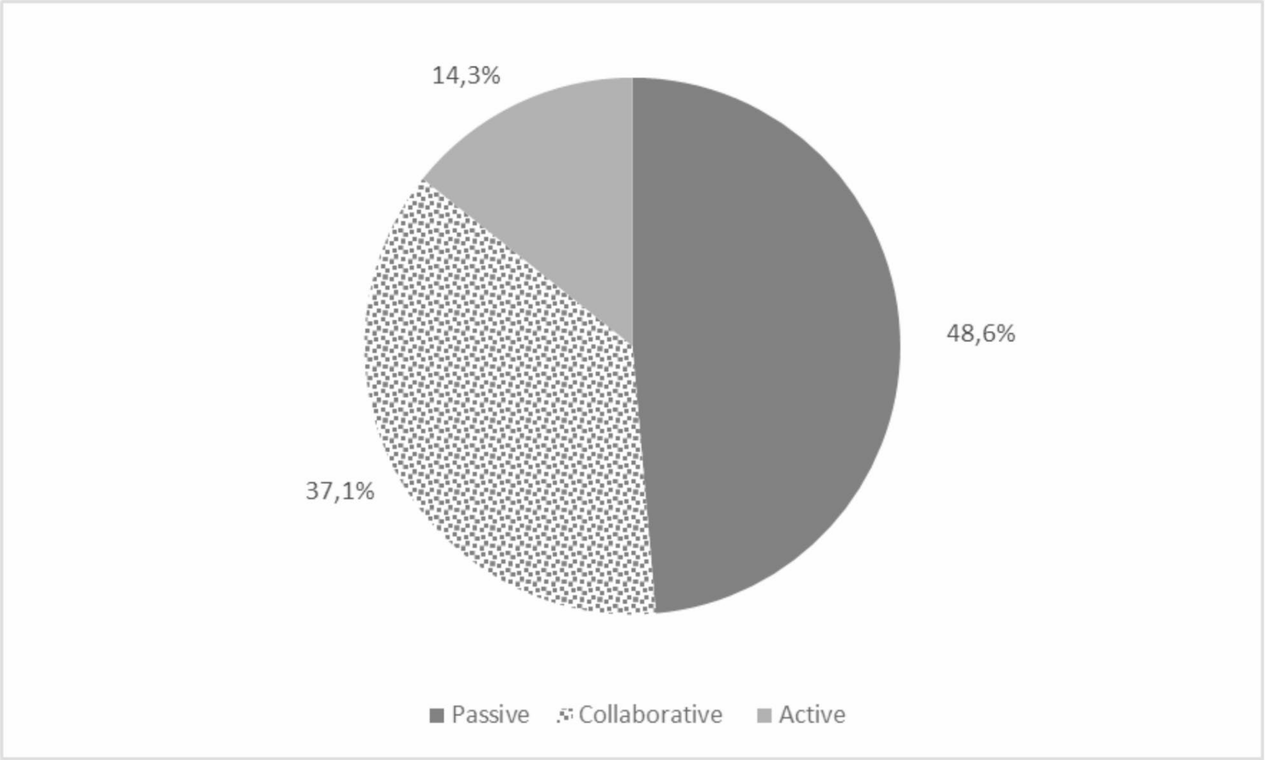

Fig. 1 Most preferred decision-making roles. Percentage distribution of caregivers' decision-making roles (*N* = 70)

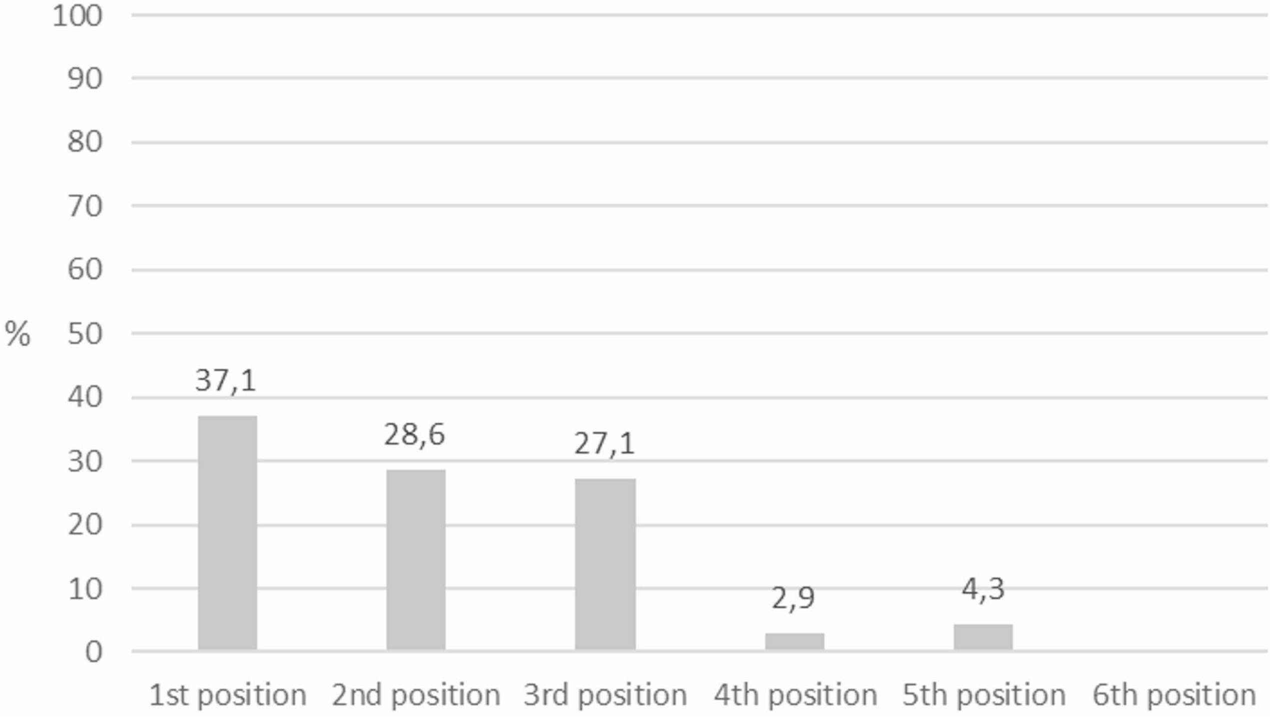

Fig. 2 Rank order of preference for a collaborative role among the six positions. Percentage distribution of how often the collaborative role was ranked by participants from 1th position to 6th position: 1 = prefer the most, 2 = second best answer, 3 = third best answer, 4 = fourth best answer, 5 = fifth best answer, and 6 = final answer (*note*: no participants put this style in the 6th position)

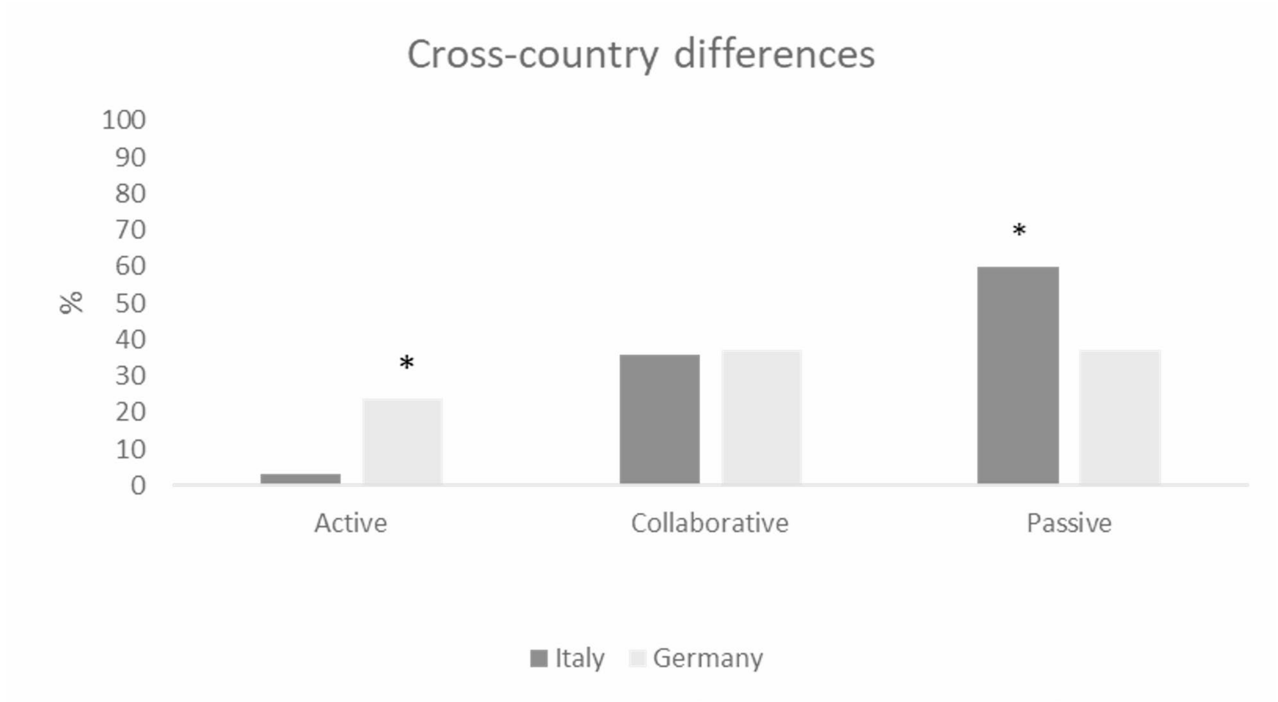

Fig. 3 Cross-country differences in decision-making preferences. Percentage distribution of preferred decision-making style. Comparison between participants in Italy or Germany

Germany. The collaborative style was evaluated similarly in both countries, with approximately 37% of participants in each sample preferring this category.

Experiences with decision-making

When comparing the confidence intervals, the percentage of participants in Italy preferring active decision-making ranged between 0% and 20.1%, while for participants in Germany it ranged between 8.1% and 41.2%. Similarly, caregivers in Italy's preference for passive decision-making (45.5%–77.7%) was higher than in the German sample (21.6%–54.7%). However, since the confidence intervals partially overlap, these differences should be interpreted with caution.

Regarding the use of the different decision-making approaches in their daily experiences with the healthcare staff, participants' responses showed various different patterns of engagement across the six decision-making approaches. In general, more collaborative approaches (such as discussing decisions together with doctors) and compliance with medical recommendations tended to receive higher levels of endorsement, while independent decision-making was endorsed less often (see Fig. 4). Specifically, 56 caregivers (80%) selected the lowest score (1) for option 1 ("I take decisions for my loved one on my own, after having considered my own wishes"), while 47 (67.1%) selected the highest score (4) for option 6 ("I comply with doctors' recommendations"). Correspondingly, mean scores ranged from M = 1.31 (SD = 0.67) for option 1 to M = 3.56 (SD = 0.72) for option 6.

ANOVA analyses comparing the two groups in both countries revealed that caregivers in Germany reported significantly more frequent use of the following options: option 2 ("I take decisions for my loved one on my own, after collecting information from doctors about the treatment options") (F(1,67) = 6.58, p =.013), option 3 ("I take decisions for my loved one on my own, after considering his/her wishes") (F(1,67) = 21.21, p <.001) and option 5 ("I inform doctors about the wishes of my loved one and doctors take this information into account when giving treatment recommendations") (F(1,66) = 13.43, p <.001) compared to their counterparts in Italy. No significant cross-country differences between countries were found for the other options (Supplementary material 4).

To explore the congruence between preferred decision-making style (the style ranked first) and reported behaviour, additional ANOVAs were conducted. Significant effects were found for option 2 "("I take decisions for my loved one on my own, after collecting information from doctors about the treatment options") (F(5,63) = 2.72, p =.027), option 4 "Doctors and I, we discuss upon and decide together about the treatment options for my beloved one" (F(5,64) = 2.90, p =.020), and option 6 "I comply to doctors' recommendations" (F(5,64) = 3.48, p =.008) (Supplementary material 5) indicating a partial but consistent alignment between preferred and enacted decision-making styles, with significant associations

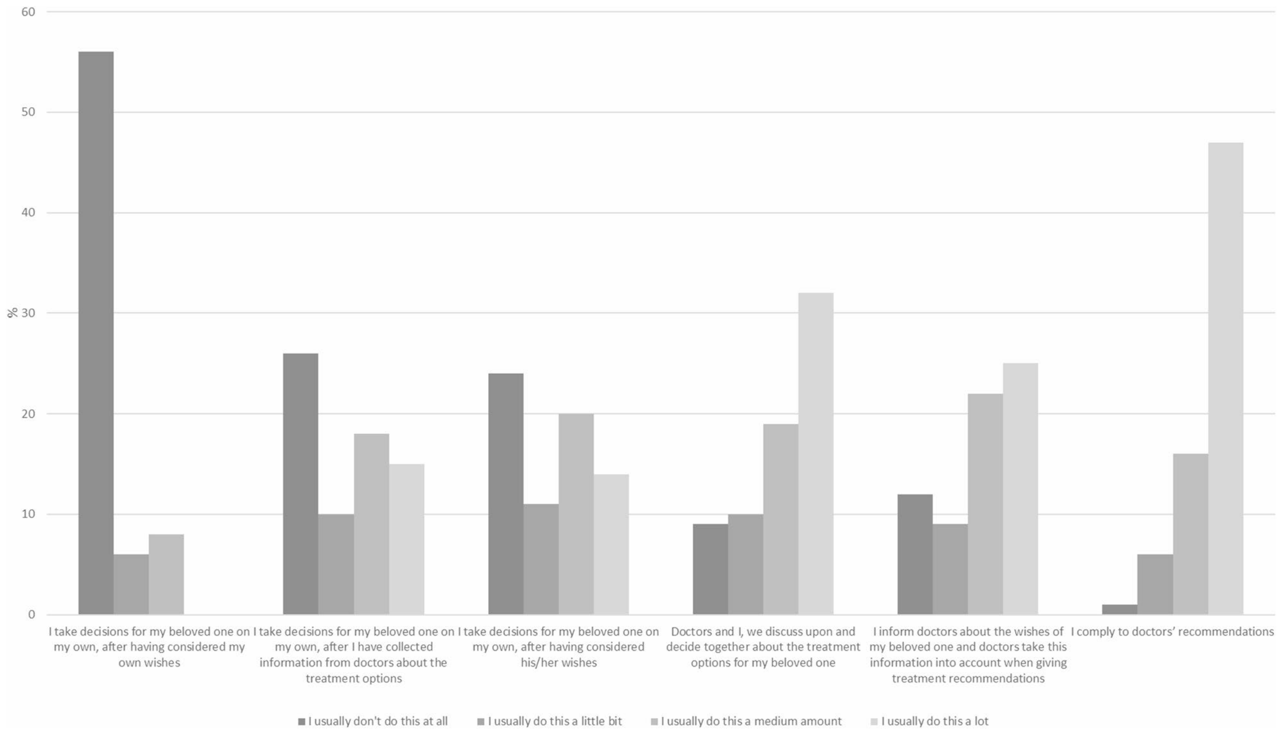

Fig. 4 Experience with decision-making. Distribution of respondents' agreement levels with statements regarding decision-making for a loved one in a healthcare context. The X-axis lists six statements describing different approaches to decision-making, ranging from making independent decisions to complying with doctors' recommendations. The Y-axis represents the proportion of respondents (%) endorsing each level of agreement. For each statement, four bars indicate how frequently respondents engage in each behavior: "I usually don't do this at all," "I usually do this a little bit," "I usually do this a medium amount," and "I usually do this a lot."

observed across the three overarching models decision-making styles.

Discussion

Preferences of informal caregivers with regard to healthcare decision-making for critically ill patients

We reported one of the first studies that investigated role preferences of informal caregivers in Germany and Italy regarding surrogate health care decision-making for persons with acquired brain injuries. It is the first we know of that is focusing on persons with DoC in early rehabilitation [33]. It included cross-country comparisons between Italian and German informal caregivers who care for people with DoC, offering valuable insights into an under-researched healthcare setting and patient population. Through this article, we contribute to a deeper understanding of SDM as a contextualized moral standard of decision-making.

Studies involving this group and this care setting are necessary because (1) people with DoC and their informal caregivers represent a unique population group and (2) the transfer from intensive care to rehabilitation is an important transition for them. Regarding (1): All syndromes within DoC are defined by decision-making incapacity and prognostic uncertainty. The syndromes differ in terms of remaining or regained abilities, but also in terms of their prognoses, which poses particular challenges for informal caregivers and, in particular, surrogate decision-makers. Regarding (2): During this transition phase, informal caregivers must participate in setting care goals for the patient that go beyond mere survival. In order to be able to participate in healthcare decisions regarding these care goals, they must develop a deep understanding of the condition of the person with DoC.

Although SDM is widely regarded as the normative standard in clinical practice, our findings reveal a discrepancy between this standard and the actual preferences of informal caregivers in two similar care settings in two different European countries. Previous studies also showed that informal caregivers of people with DoC have varying preferences for surrogate health care decision-making [32, 34]. With regard to intensive care units (ICUs), studies reported a variety of preferences but with different frequencies. A vast majority of family members of patients without decision-making capacity in ICUs in the United States had a preference for a collaborative approach to decision-making, and even preferred an active over a passive role, especially when decisions involved value-laden concerns [18, 35].

Our study revealed a high proportion of caregivers preferring a passive decision-making role, with a high proportion of a preference for an experience with a deferral of the decision to the physician. This is not easy to explain, since preferences for surrogate decision-making could be a form of personality trait (e.g. professional managers might also want to manage decisions as such) or they could be strongly influenced by contextual factors, either on a macro-level (e.g. the legal or health-care system, the socio-cultural environment), on the meso-level (e.g. implementation of pathways in the health-care environment, leadership-style of a physician) or on the micro level (e.g. personal factors accompanying the situation).

On a micro-level, anxiety and depression of caregivers of patients in ICUs has been mentioned to be more frequent in caregivers who prefer a passive role [36]. The latter findings align with research indicating that when surrogate decision-makers face high levels of uncertainty and emotional distress, they are more likely to rely on physicians for guidance [37]. In contrast to studies in the ICU, studies on decision-making with regard to the end of life decisions in the United States have similarly found a higher prevalence of passive and collaborative decision-making styles, than active styles suggesting that a majority of caregivers in highly critical medical contexts tend to prioritise medical expertise over their own authority with regard to health care decision-making [36, 38]. In comparison, studies on role preferences of patients with a different neurological condition such as multiple sclerosis -who in contrast to our sample can still mostly make decisions for themselves- entail higher levels of preferences for an active or collaborative style [28, 29].

On a meso-level, differences in health care settings, such as ICU versus early neurorehabilitation, may partly shape caregivers' decision-making preferences. For instance, physicians in the ICU might have adopted different approaches to involving caregivers in decision-making before the patient's transfer to rehabilitation. It is known that physicians can seek different degrees of influence on the decision-making process, e.g. due to the decision-making standard in a healthcare setting, and consequently could be opening or limiting the freedom of family caregivers to make the health-care decisions for their loved one. A study in ICUs for children with prolonged DoC in Switzerland showed that even when physicians believe to adopt SDM, they incorporate different approaches such as either giving the patients the maximum freedom until the physician deems it necessary to limit it (the "brakes approach"), by leading the conversation actively (the "orchestra director" approach) or by trying to reach a consensus through employing their own experiences and qualities (the "sunbeams approach") [39] . A study from India has shown that the implementation of a structured guideline for family-centred care (including SDM) for patients with acquired brain injury in the ICU can influence decision-making and even lead to a higher satisfaction of family caregivers with decision-making [40].

On a macro-level, the two sub-samples from Italy and Germany were comparable with regard to most attributes, but a notable difference occurred in the proportion of legally appointed surrogates. Almost all participants in Germany were legally appointed surrogates, compared to only slightly more than half of those in Italy. This difference can be attributed to the timing of the survey in the illness trajectory. In Italy, the lower proportion of legally appointed surrogates may reflect not only slower procedural differences -such as longer and more formal judicial pathways- but also cultural and structural differences, including less widespread use of advance directives [41], a more formal and judicial process for legal guardianship, and the more common acceptance of informal caregiving roles without immediate legal formalization. In contrast, in Germany, the process tends to be more streamlined and flexible, as a power of attorney is widely used and considered legally equivalent to a legal guardian appointed by the court. As a result, informal caregivers in Germany take over the role as surrogate decision-makers earlier in the course of the illness trajectory which could account for the higher numbers of preferences for active or collaborative roles than in the Italian sample where a higher number of preferences for passive roles were prevalent. Maybe the demand of an active participation in decision-making could lead to suitable role preferences. A different explanation could be that there are cultural differences that lead to different processes of appointing a legal surrogate.

Regarding decision making preference frequencies, we found very low rates of a preference for deciding based on caregiver's own wishes, a result that may be either valid or influenced by social desirability bias [42]. Caregivers may underreport their own preferences in favor of responses that align with perceived societal or moral expectations -such as prioritising the patient's wishes or best interest- thus masking the complexity of real-life decision-making dynamics. Other studies pointed out the possibility of biases which might still unconsciously influence surrogate decision-making. It was assumed that surrogate decision-makers may be prone to errors due to projection bias, in which they unconsciously or consciously substitute their own beliefs, preferences, or values for those of the patient. This cognitive distortion might lead to decisions that reflect what the surrogate would choose, rather than what the patient would want or what is in the patient's best interest. Recognising and addressing projection bias is crucial to ensuring truly patient-centred decision-making [30, 31, 43].

What normative imperative follows our findings? It is clear that we cannot conclude what should be because it is preferred alone (is-ought-problem). Yet, if we combine the finding with a bridge principle, a normative conclusion towards incorporating a more paternalistic approach to decision-making in Italy is at least not illogical. We could argue for this position based on a majority principle. It is described as follows: "If, ceteris paribus, X (= empirical result) indicates that the majority of a group/population believes that an action should be done or a goal should be reached (= normative premise), then it is justified to conclude Y (= normative conclusion)" [p.7] [44] . This means in our case, if a majority of informal caregivers in Italy prefers a passive approach to decision-making based on a majority principle, we should offer the group or caregivers -by default- a paternalistic approach to decision-making. However, the bridge principle itself is in need of additional premises for its justification and there are good reasons to rather argue for trying to change the caregivers' preferences in light of the many uncertainties in such a situation, which will be explained further in the next section.

Considerations of control-preferences when approaching technology-informed decision-making

When implementing a new technology such as multimodal testing in the context of DoC, the question arises how caregivers and physicians should then approach health care decision-making about the goals of care. Such decisions are made under high levels of uncertainties as prediction of rehabilitation outcomes -even with enhanced prediction accuracy- still produce high false-negative as well as false-positive rates. Furthermore, multimodal testing could reduce uncertainty in prognostication but also create new ambiguities that might be difficult to interpret. Different modalities for testing could indicate different diagnoses within DoC. This question needs to be answered based on ethical considerations.

In general, in health care decision-making for patients with DoC which concern the goals of care (including decisions regarding forgoing life-prolonging treatment), uncertainty emerges as a central and pervasive challenge. Understanding the many dimensions of uncertainty is essential for decision-making processes. Uncertainty in this context can be broadly categorised into scientific, personal, practical, ethical, and social dimensions [16, 32]. Scientific uncertainty arises from ambiguous prognoses and disagreements among professionals, which can impede communication between medical teams and caregivers. Scientific uncertainty could be mitigated by multimodal testing -when results in different modalities point in the same direction- but it could also arise from contradicting results in multimodal testing. Personal uncertainty involves the psychosocial and existential consequences of continued treatment, particularly in cases of severe impairment. Practical uncertainty concerns challenges such as limited access to specialised neuro-rehabilitation services and the financial burden of long-term care. Ethical uncertainty arises from navigating conflicting medico-ethical principles -such as respect for autonomy, beneficence, nonmaleficence, and justice- particularly when patient preferences are unknown or ambiguous. For instance, respecting a patient's prior wishes may be difficult if those wishes were never documented, a situation that is especially relevant for younger individuals and in countries where advance directive legislations were passed more recently. At the same time, the principles of beneficence and nonmaleficence are complicated by uncertain or changing prognoses (e.g. due to complications in such a pulmonary embolism), and justice may require balancing individual care needs with resource constraints in health care systems. Social uncertainty introduces another layer of complexity, reflecting how caregivers' subjective beliefs -such as those regarding the presence of consciousness, the potential for communication, or the likelihood of recovery- can override the portrayal of neuroscientific or clinical information and known patient preferences. Such caregiver illness beliefs can have a strong influence on surrogate decision-making [16, 32].

The findings of this study suggest that the role preferences of informal caregivers for persons with DoC can vary between the two countries or facilities respectively, but also across the participants within a country/centre, adds a new layer to the social uncertainty accompanying health care decision-making about the goals of care for people with DoC. As Curtis and Tonelli (2011) pointed out, for a health care professional this means that "there are some family members who endorse each possible role on the spectrum of decision-making roles, ranging from desiring total control to deferring completely to clinicians" (p. 840) [18]. This could lead to communication uncertainty on the side of the physician, who then is either hesitant to include family caregivers in decision-making or is assertive and so risking overburdening family caregivers with responsibility that they do not want to take over. It is not necessarily the best option to ask caregivers openly for their role preferences in goal-of-care decision-making in the early stage of rehabilitation because surrogate decision-making could be unprecedented and their experience in the ICU could have shaped their preferences towards a certain role. A more suitable approach would be to allow informal caregivers to explore different roles in decision-making while adjusting to the situation.

Claassen argues in light of advances through multimodal testing that "decision-makers including families and healthcare providers must understand and embrace" predictive uncertainties (which are part of scientific uncertainty) (p. 7)[45]. He considers SDM to be a promising approach and recommends conducting studies that incorporate SDM models. Specifically, Muehlschlegel et al. (2022)[45]. investigated the feasibility, acceptability and usefulness of decision-aids for goals-of-care communication with surrogate decision makers for critically ill patients with severe acute brain injury in the USA and reported that 96% rated them as useful. A current US-American guideline of the American College of Critical Care Medicine (ACCM) and American Thoracic Society (ATS) goes even further recommending SDM for surrogate decision-making in the ICU in general [46]. It entails the recommendation that "clinicians should use SDM as their 'default' approach, and they understand SDM as a specific process that includes three main elements: information exchange, deliberation, and making a treatment decision" (p. 188) [46]. Their argument is based on similar studies as ours but their studies showed that a majority of surrogate decision-makers for critically ill ICU patients preferred a collaborative approach. Additionally, they argue that to incorporate SDM means understanding the patient as a person, with values, goals, and preferences that are essential for the decision-making process. This calls for interventions to foster the health literacy and involvement of informal caregivers, when implementing such novel approaches to diagnosis, prognosis and surrogate medical decision-making, such as authors of this publication and others suggested recently [46].

At the same time the authors of the guideline recommend that "clinicians should tailor the decision-making process based on the preferences of the patient or surrogate" (p.188) [46]. When suggesting a tailored approach to decision-making, they are pointing out that preferences might vary not only between family caregivers but also in points of time and suggest that clinicians should then accommodate caregivers' preferences. This raises the question, whether it would also be justifiable to support or even to persuade a surrogate decision-maker to take over other roles than the one they initially preferred when being confronted with complex surrogate decisions with high-stakes. The above-mentioned uncertainties warrant a decision-making approach in which not only the rights but also the obligations towards the patient are shared among the two parties. Does a physician have a right to conduct SDM? Should they be allowed to refrain from taking over the decision-making authority when caregivers defer the decision to them because it would burden their conscience? If close family members experience significant emotional distress when asked to participate in decision-making that could result in the patient's death, their distress could be managed through professional support or they could appoint a person who is either trained for such situations or who is a person of trust in their private life and then is supporting informal caregivers in upholding their role. Should physicians accommodate decision-making preferences that are highly technical and hence impractical (decision about an antibiotic) or that violate their ethical obligations towards the patient (a caregiver preferring to decide themselves, but their decision is based on unreasonable assumptions) [17]? Such questions need to be answered in future studies based on ethical considerations especially when implementing novel and complex health technologies which could influence decision-making about the appropriate health care strategies for people with DoC [47].

Limitations

This study has several limitations. The COVID-19 pandemic created unprecedented challenges in study participant recruitment. It led to a small sample size, which also has affected the statistical power of the analysis of the data. It hindered the study team in realising a longitudinal approach to investigating how preferences might change in the course of the rehabilitation care, especially in cases where multimodal testing leads to a different diagnosis than behavioral testing alone.

Moreover, supplementary analyses, specifically the group comparison conducted through ANOVA, were limited by highly unbalanced group sizes which, along with the exploratory nature of the analysis, restricts the interpretability of the findings. Further research is needed to better understand the discrepancies between stated preferences and actual behaviour, which may reflect contextual constraints—such as clinical hierarchies, limited information, or caregiver uncertainty—that were not accounted for in the present study.

While we could identify two prior studies which applied the CPS specifically to surrogate decision-making [35, 48], our study employed a modified version of the original psychometric test [24]. The instrument was used for the first time within this study and was not previously validated in its English form (used in this publication) nor in its German and Italian translations (actually used in the study). The questionnaire was adapted from a version originally designed for patients, and had to be adapted to caregivers of critically ill individuals. At large the two instruments are similar, but ours included a new item which was especially focused on a possible conflict of interest between respecting the preferences and values of a caregiver and the prior preferences and values of a person with DoC leading to an unbalanced number of items per role (three that referred to the active, two that referred to the passive role and one that referred to a collaborative role). The modifications to the CPS (wording adjustments, and the addition of a new item) may affect direct comparability with studies using the original version, and could potentially alter the construct being measured. However, these adaptations were necessary to ensure comprehensibility and relevance for informal caregivers of patients with DoC in two different cultural contexts. While this increases ecological validity, it also introduces limitations regarding measurement validity that should be taken into account when interpreting the findings.

Since it is the first study that investigated the role preferences of surrogate decision-makers of informal caregivers of people with DoC, we need further research to validate the developed instrument in similar settings with larger numbers of participants. Future research could explore correlations of this instrument with personal factors that might influence such preferences, such as caregiver stress, coping strategies, trust in health care providers, need for autonomy or previous experiences with (shared) medical decision-making.

Conclusions

Healthcare professionals should be attentive to the diversity of decision-making preferences expressed by family caregivers of patients with DoC shortly after the transition from intensive to rehabilitation care. Although SDM is widely regarded as the normative standard in clinical practice, our findings reveal a discrepancy between this standard and the actual preferences of informal caregivers in two similar care settings in two different European countries. A majority in this study preferred a passive approach to decision-making. In surrogate decision-making about the goals of care for patients with DoC however, there are good reasons to actively promote SDM especially when implementing multimodal testing in neurological rehabiliation. While a collaborative approach was not the predominant first-choice, it ranked highly across respondents. Especially in Germany, physicians can expect that informal caregivers prefer active or collaborative roles over passive approaches to decision-making, while preferences might vary from case to case. Helping family caregivers understanding the benefits and challenges of multimodal testing of people with DoC calls for interventions to foster the health literacy and involvement of informal caregivers, when implementing novel approaches to diagnosis, prognosis and surrogate medical decision-making.

Abbreviations

DoC	Disorder(s) of consciousness
UWS	Unresponsive wakefulness syndrome
MCS	Minimally conscious state
FC	Family caregiver (might be understood in a way that excludes friends)
IC	Informal caregiver (more general term)
ICU(s)	Intensive care unit(s)
SDM	Shared decision-making

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

AC, MB, AB and JDS designed the study. AC, MJR, CV, LW, PO, AB acquired the data in the three centers. MB and CV conducted the analysis of the data. CCD and KK drafted the manuscript, CCD generated the tables and figures, AC, MB, MJR, CV, LW, PO, AB, MR and JDS revised and CCD and KK revised and finalized the manuscript. All authors approved the final version of this manuscript.

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Data availability

The datasets generated and analysed during the current study are not publicly available due to ethical restrictions. However, anonymised and/or aggregated data can be made available by the corresponding author upon reasonable request, exclusively for scientific purposes, in accordance with the Ethics Committee approval.

Declarations

Ethics approval and consent to participate

Ethics approval for the study was obtained in both countries from the relevant Institutional Review Boards: the Ethics Committee of the Medical Faculty at LMU Munich, Germany (protocol numbers 20–634 and 20–635), and the "Comitato Etico IRCCS Fondazione Don Carlo Gnocchi" of the IRCCS Regione Lombardia, Italy (protocol number 32/2021/CE_FdG/FC/SA). Written informed consent was obtained from all participants prior to their inclusion in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Publisher's Note

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