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Original Study

Challenging Yet Rewarding: Staff Experiences in Prolonged Disorders of Consciousness Rehabilitation

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ABSTRACT

Objectives: This study explored the experiences and needs of health care professionals providing specialized neurorehabilitation for patients with prolonged disorders of consciousness (PDOC) in post-acute and long-term care settings.
Design: A qualitative study within the nationwide PDOC chain-of-care, including early intensive neurorehabilitation (EIN) in one rehabilitation center and prolonged intensive neurorehabilitation (PIN) in 3 specialized nursing homes up to 2 years post-injury.
Setting and Participants: Fifty-two health care professionals (nurses, physicians, and rehabilitation therapists) aged $\geq$18 working at either EIN or PIN with at least 1 year working experience in PDOC care were included.
Methods: Five discipline-specific focus group discussions, 2 in-depth interviews, and 9 written testimonies were conducted between November 2021 and May 2022. Data were thematically analyzed.
Results: Five themes describing rewarding aspects—*complexity of work, providing meaningful care to patients,* supporting *families, multidisciplinary collaborations within teams and care network, works' personal impact, and professional enrichment*—and 4 themes describing challenging aspects—*confrontation with patients' condition and families' grief, moral distress, complex interaction with families, personal and professional impact*—were identified. For sustainability, health care professionals need improved working conditions, specialized training (especially communication skills and resilience trainings), and psychological support to deal with both families' expectations and moral distress. They also urged for better family support systems and improvement in care procedures.
Conclusion and Implications: This study emphasizes the challenging yet rewarding nature of specialized neurorehabilitation for patients with PDOC and its impact on health care professionals while highlighting their unmet needs. These insights can be implemented to improve existing care programs and establish criteria for institutions delivering this care. Acknowledging burdensome aspects of this work, investment in the well-being of professionals by their employers and policy reforms focused on improved working conditions, specialized training, and psychological support is crucial for sustainable and resilient PDOC care.

Keywords:
Prolonged disorders of consciousness rehabilitation
health care professionals
experiences
impact

Long-term care is a challenging yet rewarding work environment. In specialized settings, this duality in health care professionals' experiences can be observed in extremis. Prolonged disorders of consciousness (PDOC) are among the most serious outcomes of acquired brain injury, with patients requiring long-term intensive multidisciplinary care.[1]

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PDOC, an umbrella term for altered states of consciousness, includes the unresponsive wakefulness syndrome (UWS, also known as the vegetative state) and the minimally conscious state (MCS).[2–4] Although awake, UWS patients show no signs of awareness of themselves or their environment, whereas MCS patients exhibit inconsistent yet reproducible response to external stimuli including simple command following, intelligible communication, or purposeful behavior.[5]

Multidisciplinary, specialized neurorehabilitation is a prerequisite for recovery from PDOC.[6–8] Such care is physically demanding and medically complex, requiring diagnostic and therapeutic expertise and moral resilience.[9,10] Caring for severely disabled, uncommunicative patients and witnessing their families' psychological distress can be burdensome for health care professionals.[11–13] Amid prognostic uncertainty and the absence of the patient as a partner in decision-making, health care professionals are faced with families' grief, hope, and needs.[14–18] These challenging aspects, however, may be paralleled by improvement in the patient's condition, supporting families, team quality, complexity of the work, and positive personal impact.[19] Working with PDOC patients is associated with a moderate to high burnout rate in rehabilitation centers and nursing homes.[20–22] Being a nurse, young age, working in a nursing home, lack of either job-specific training or confidence in professional capacities, and moral distress arising from providing care against one's personal and professional values are known risk factors for burnout.[12,13,20–22] The recognition of burdensome aspects of work and taking measures that contribute to supporting professionals and their employability is crucial for sustainable health care, especially for rare patient populations like PDOC. However, there is a paucity of qualitative studies investigating and addressing the experiences and needs of professionals working in PDOC care. Health care systems globally struggle delivering long-term PDOC care due to factors such as staff shortage, burnout, limited finances, fragmented care, and restrictive legal or policy frameworks.[23] Addressing these issues and preventing turnover among highly qualified professionals involved in this care requires a coordinated multilevel governance approach, and a better understanding of their needs.

The Netherlands has a long tradition of professional and academic post-acute and long-term care, which includes specialized neurorehabilitation for PDOC. Expertise network EENnacoma and its recently developed unique nationwide PDOC chain-of-care with an integrated knowledge infrastructure is an example of a collective effort of clinicians, researchers, health care organizations, and policymakers facilitating early intensive neurorehabilitation (EIN) for 14 weeks in a rehabilitation center led by a physiatrist and prolonged intensive neurorehabilitation (PIN) in 3 specialized nursing homes for a maximum of 2 years post-onset under supervision of an elderly care physician (Figure 1).[24–28] Combining rehabilitation and long-term and palliative care, these professionals face multiple challenges in modern post-acute health care.

Objective

To explore the experiences and needs of health care professionals involved in specialized neurorehabilitation of PDOC patients and their families.

Methods

Design and Setting

This qualitative study is a part of the True Outcomes of PDOC (TOPDOC) project, a multicenter cohort study performed within the specialized PDOC chain-of-care.[25] For reporting of the qualitative data, Consolidated criteria for reporting qualitative research (COREQ) guidelines were used (Supplementary Table 1).[29]

Participants

Health care professionals aged 18 years or older working in either EIN or PIN with at least 1 year working experience were included, for example, nurses and nurse assistants, physicians, physician assistants (PAs), and rehabilitation therapists (RTs), such as physiotherapists, language and speech therapists, occupational therapists, psychologists, social workers, music therapists, and dietitians.

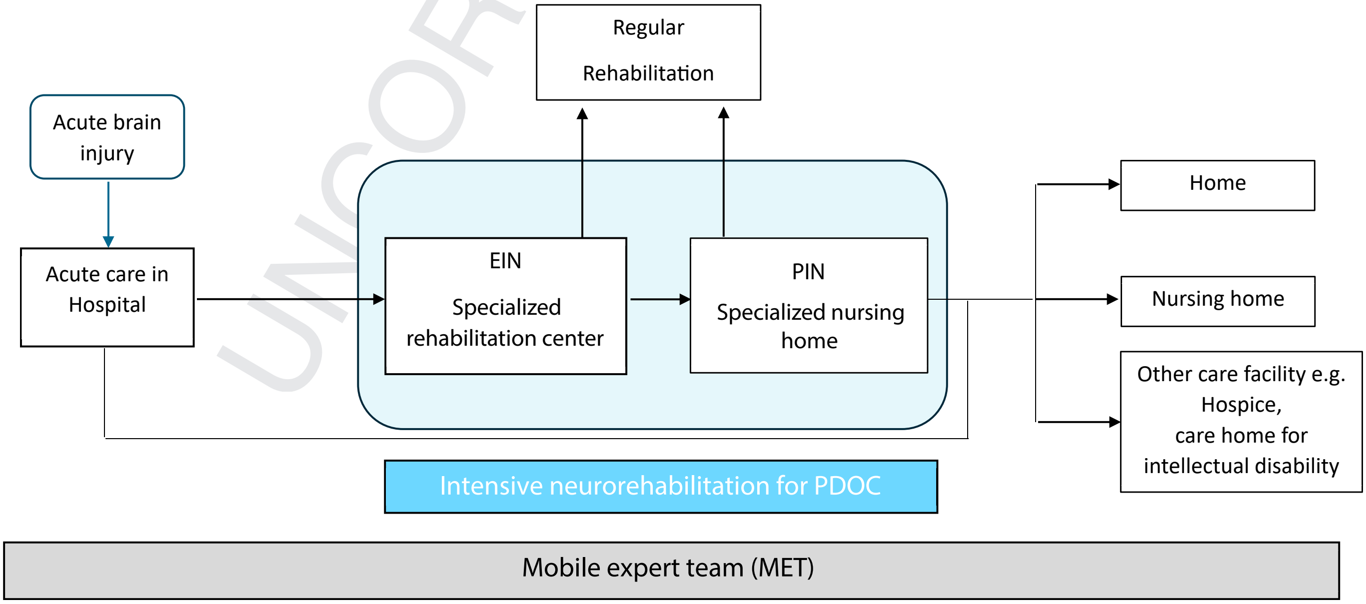

Fig. 1. PDOC chain-of-care in the Netherlands.[24] EIN, early intensive neurorehabilitation duration maximum of 14 weeks; MET, mobile expert team for onsite PDOC diagnosis and consultation; PIN, prolonged intensive neurorehabilitation up to 2 years post injury.

Data Collection

Data were collected between November 2021 and May 2022 by direct observation of working conditions in EIN and PIN, focus group discussions, in-depth interviews, and written testimonies from participants.

Procedure

All eligible candidates provided their written informed consent before participation. Five discipline-specific focus groups with a maximum of 11 participants, were held: 1 with physicians and PA, 2 with RT, and 2 with nursing staff. Due to COVID-19 regulations, 1 session was held online. Four focus groups were facilitated by an experienced moderator and medical ethicist (J.v.G.) and observed by an elderly care physician working in PIN (M.S.-V.). One focus group was moderated by M.S.-V. Three professionals subsequently participated in 2 semi-structured interviews conducted by M.S.-V. and 9 participants wrote a testimony. Focus groups and interviews used a predefined set of questions (Box 1), were audio-recorded, and lasted on average 90 and 60 minutes, respectively.

Data Analysis

Audio recordings were transcribed verbatim and managed with CAQDAS ATLAS.ti 22.15. Using thematic analysis, data were open-coded independently by 2 investigators (M.S.-V. and A.O.B.).[30] Initial coding identified themes and patterns across the data relevant to the research questions, while considering new insights regarding participants' experiences in PDOC care. Consensus was reached by discussion and comparison of the initial codes from 2 focus group transcripts. These codes were subsequently applied to the remaining transcripts. In an iterative process, codes were refined and adjusted by adding information from subsequent transcripts. After coding focus groups and written testimonies, data saturation was reached as no new codes emerged from interviews. Ongoing intensive discussions with the whole research team resulted in further refinement and finalization of study themes. Triangulation of the data source and researchers helped improve validity of results.

Ethical Approval

The regional ethics committee Arnhem-Nijmegen (file number: 2021-7338) deemed this study exempt from further screening.

Results

Fifty-seven health care professionals provided written informed consent. Five participants opted out either due to inability to participate on the planned date or personal circumstances. Eventually, 52 health care professionals—86.5% female, mean age 42.6 years—participated in this study (Table 1). Fifty percent of participants were RTs, 28.8% nurses, and 21.2% physicians or PAs, with a mean working experience of 5.9 years in PDOC care and 71.2% working in PIN. All physicians currently working in EIN and PIN participated in the study. The experiences and needs of health care professionals in both settings were broadly comparable. Where relevant, differences between settings and disciplines are explicitly indicated.

Box 1. Key Questions Discussed in Focus Groups, In-Depth Interviews, and Written Testimonies

- *What are your positive and negative experiences of working with PDOC patients and their families?*
- *What is the impact of this work on your professional and personal life?*
- *What is in your opinion required to sustain?*

Five themes concerning rewarding aspects and 4 themes describing challenging aspects of working with PDOC patients and works' impact on personal and professional life and associated subthemes were identified (Table 2).

Rewarding Aspects of Working With PDOC Patients

Complexity of Work

Participants describe their work as "fascinating" and "challenging" simultaneously. Individualized patient approach and the absence of protocols appeals to professionals' creativity and pioneering ability. They enjoy solving the "complex puzzle" that each case presents, discovering new ways and pushing themselves to the limits to help patients achieve a higher consciousness level. Participants take pride in dealing with works' complexity that encompasses diagnostic, therapeutic, prognostic, and ethical challenges as "everything literally comes together."

Providing Meaningful Care to the PDOC Patient

Nurses describe their extraordinary "one-sided relationship" with a care-dependent, noncommunicative patient, built by observing behavioral or physical signs and discussing it with the patient's family. While empathizing with the patient's vulnerable condition, participants also celebrate the small improvements in the patient,s condition along with patient's family. Putting team effort and working on collective goals directed at the patient's recovery is perceived as "meaningful." If, despite all efforts, further recovery is impossible, nurses and physicians feel privileged in providing compassionate palliative care and alleviate prolonged suffering.

Guiding and Supporting Families

Supporting and reinforcing families of PDOC patients is considered as an indispensable task. Physicians portray their complex multifaceted role in informing families about the patient's medical condition, discussing prognostic uncertainty and guiding them through the decision-making process. RTs appreciate the collaboration with patients' families during therapy sessions. Nurses cherish the beautiful interactions during guidance of families in finding a new balance in their role and relationship with the patient. The gratitude of families toward professionals in turn enhances both motivation and job satisfaction.

Multidisciplinary Collaboration Within Teams and the PDOC Chain-of-Care

An interdisciplinary approach is considered one of the most important and rewarding aspects of this work, allowing professionals to learn from each other's expertise and contribute both in team building and a safe working environment. There is an overall sense of pride and belonging experienced in being a part of a unique national care network. Participants appreciate the short communication lines and collaboration between teams and network, working together on collective goals and shared responsibility to ensure improved standards of PDOC care.

Personal Impact and Professional Enrichment

Participants describe both personal transformation and enrichment of professional expertise due to continuous development of their knowledge and skills. Confrontation with life's vulnerability is a humbling and valuable aspect of this care, allowing participants to put things into perspective and appreciate their own health and well-being. They report becoming more indulgent at home and enjoying

Table 1
Participant characteristics (N = 52)

	Total	Nurses	RTs	Physicians/ PAs
Total (%)	52	16 (28.8)	26 (50)	10 (21.2)
Mean age, y (range)	42.6	36.6 (22–60)	43.6 (25–63)	49.3 (35–61)
Gender, female (%)	45	16 (100)	22 (84.6)	7 (70.0)
Mean work experience, y (range)	5.9	6.8 (2–36)	5.0 (1–11)	6.5 (2–20)
Work settings (%)	EIN = 28.8 PIN = 71.2	EIN = 26.7 PIN = 73.3	EIN = 26.9 PIN = 73.1	EIN = 36.3 PIN = 63.7

EIN, Early Intensive Neurorehabilitation; PIN, Prolonged Intensive Neurorehabilitation; PA, Physician assistants in EIN setting.

life's smaller pleasures. Some participants have documented or discussed their living will with their families.

Challenging Aspects of Working With PDOC Patients

Confrontation With the Patient's Condition and Families' Grief

Participants find working with PDOC patients confronting due to patients' youthful age, severe disability, and inability to communicate. They relate the fate of these young patients to themselves or their own family. Participants experience a sense of helplessness resulting from the inability to ask the patients whether they still find their situation bearable. Absent patient interaction is a reason for some participants to consider switching their job. Seeing no progress or regression in a patient's condition caused by recurrent medical complications and multiple patients simultaneously not improving during rehabilitation is particularly demoralizing. The impact of these aspects is further augmented when confronted with the emotional burden and grief of patients' families.

Moral Distress

RTs sometimes experience distress in continuing burdensome interventions that they perceive as mistreatment or even harassment of a vulnerable and incapacitated patient who is unable to object. Participants question the purpose of these treatments and feel troubled by the idea of making someone aware of their disabilities, particularly in case of younger patients and in the absence of one's predetermined will. They express concern about an emerging group of patients who are falling between the cracks—namely, those who regain full consciousness but are ineligible for regular rehabilitation because of physical and cognitive impairments. EIN participants feel concerned about the cost-effectiveness of rehabilitation and the strain on already scarce health care resources.

Complex Interaction With Families

Participants describe several challenging aspects of communication with patients' families. Addressing emotionally charged themes such as discontinuation of rehabilitation or end-of-life decisions, communication with complex family systems involving more than one legal representative or divorced parents is perceived as difficult. Misunderstanding or distrust from patients' families, their frequent or unrealistic demands, disagreement about treatment duration or goals, and inappropriate or aggressive behavior are a significant source of job dissatisfaction and demoralization among participants. Nurses in particular report undervaluation of their efforts and bashing from families. Skepticism, denigration, and transgressive behavior are more frequently reported in PIN than EIN settings. Two PIN caregivers had received death threats from patients' families, with substantial personal and professional impact.

Work's Personal and Professional Impact

Shortage of staff with PDOC expertise results in a high workload and psychological strain for several participants. Experiencing a deep sense of personal responsibility, they feel falling short in face of continued job demands. The inability to detach and taking work-related issues home is a source of psychological distress for some participants. Participants disclose overprotectiveness at home or even doom-thinking originating from their experience at work, resulting in self-avoidance or forbidding their children to participate in certain activities, like horse riding.

Needs of Health Care Professionals

While portraying barriers and facilitators in care provision, participants elaborated on what they felt is required to sustain themselves. Five themes were identified describing these needs (Table 3).

Working Conditions

Staffing problems (nurses in both settings and RTs in PIN) and insufficient personnel with PDOC expertise is a recurring problem. PIN participants suggest a minimum occupancy of 2 persons per discipline to ensure continuity and quality of care. Recruiting new employees and retaining staff is crucial for team stability in both settings. Participants also request improved practical facilities and manageable workload. Part-time work and working at different wards are described as beneficial to recharge and sustain longer.

Psychological Support

Participants highly appreciate their teams, seek support in each other, and highlight the importance of a safe team environment for sustainability. Appreciation and support from both colleagues and executives keep the professionals motivated and going. Structural psychological support and (team) coaching aimed at dealing with work's psychological impact and moral distress is currently lacking and underscored by participants from both settings. Professionals particularly need informal sharing moments with colleagues, frequent and on-demand moral case deliberations, and interdisciplinary complex case discussions for which they request facilitation from their employers.

Training and Professional Development

Participants recall obstacles experienced as a newcomer due to the absence of PDOC-specific training. They request development of PDOC-specific education programs, on-job training, and appreciate learning opportunities during work-visits. Participants specifically request training to improve their communication skills required to better support bereaved families but also to assist themselves in dealing with families' demands without straining their professional relationship. Importantly, professionals feel an urgent need to be better protected against aggression and other forms of intimidation at work and request resilience training to deal with inappropriate behavior of families.

Better Support for the Patient's Family

Participants unanimously recognize the extraordinary burden and needs of patients' families. They believe that addressing family needs can eventually improve their own working conditions. Participants

Table 2
Rewarding and Challenging Aspects of Providing Care to PDOC Patients

Topics	Themes	Subthemes	Quotations
Rewarding aspects of providing care to PDOC patients	Complexity of work	Pioneering and solving the puzzle together, diversity and dynamics	*"Because I like solving puzzles, finding out what exactly is going on and figuring out how to treat someone in such a way that they start to improve in their consciousness level. And that's different with everybody." FDRT1#6.*
	Providing meaningful care	Overjoyed seeing recovery, gratifying to provide palliative and end-of-life care	*"To us, it is a big deal, although it may be a very small (change). Suddenly a hand that is moving again, or someone making a very slight movement. You see a change in the look. Otherwise, it is someone who looks straight through you. Then suddenly you see someone actually looking at you." FDN1#4.* *"Sometimes in the situation that they are in, it is gratifying to be able to provide support." FDN1#1.* *"If you can provide compassionate care during the process of the dying, and support the family as well in that process, it actually feels a kind of victory. A kind of beautiful moment that the person has finally found some peace and no longer has to suffer." FDN1#4.*
	Guiding and supporting families	Coaching families, collaboration with family during therapy sessions, gratitude of family	*"[It] is a very heartbreaking process, if you have to face the fact that someone is not recovering, but if you succeed in letting go of someone in a respectful way, which is also quite wonderful and a part of the process. However, it can also be the most challenging part of this care." FDP#4.* *"I do want to emphasize that I really like it how you actually give [the family] the grip on the situation again, right? After the hospital phase they often have no idea what they can or should do and whether it is right or wrong. And I find it really rewarding that you can guide them through this and see their self-confidence grow." FDRT1#3.*
	Multidisciplinary collaboration within teams and PDOC chain-of-care	Collaboration in unique PDOC chain of care; multidisciplinary approach, safe working environment	*"It feels like a collective responsibility and although you obviously have your individual areas of expertise and tasks or roles, you really work together on achieving the same objectives. This also helps me personally to experience reduced workload." WTRT#3.*
	Personal impact and professional enrichment	Aware of life's vulnerability, putting things into perspective, development of professional skills	*"Yes, and on the one hand you see a lot more dangers. You know what can go wrong and on the other hand you start to appreciate more things." FDN2#9.* *"Work also does help you put things into perspective, I think. Just when you find yourself saying something like oh, it could be far worse." FDN2#5.*

(*continued on next page*)

Table 2 (*continued*)

Topics	Themes	Subthemes	Quotations
Challenging aspects of providing care to PDOC patients	Confrontation with patient's condition and families' grief	Young age, inability to communicate, seeing severe disability and discomfort of patient, witnessing grief and distress of family	*"But I do believe that, as you keep getting case after case that are just really poignant, that you do end up with some kind of scars on your care heart." FDN1#1.* *"And what I find most difficult about that is that you cannot discuss it with the patient—'Can you still bear this? Can you still go for that?'" FDRT2#7.*
	Moral distress	Watching stagnation in recovery process, providing therapy means harassment of a vulnerable patient and prolonging of suffering, feeling distressed about making someone aware of his/her own severely disabled condition	*"That feels to me like the main moral dilemma. My gut instinct tells me they have absolutely no benefit here that I'm taking them to some device, but often there is then a partner in the background or a parent who is right on top of it and just wants to maintain those therapies. I feel like I am being abusive to the patient, I am harassing them." FDRT1#1* *"Yes, conscious, but it still is truly little that they can do. And I think, what are we doing it for? […] Especially for those young people, those in their twenties. I think, would they really have wanted themselves to end up in a wheelchair, dependent on 24-hour care, not being able to communicate and you can no longer do anything spontaneously yourself?" FDP#3.*
	Complex interaction with families	Dealing with family's distrust and undervaluation, unrealistic demands and conflicts, communicating end of rehabilitation and treatment decisions, complicated family system	*"Some relatives are looking with a magnifying glass at all my actions and are judging and sometimes even on the spot convicting me. It sometimes takes a while to get there before you are in harmony with them, and the relatives have confidence in me as an individual and in us as a team. And witnessing no progress during therapy, well, they often blame that, or at least that's how I feel, that they blame that on us." FDRT1#10* *"Sometimes family simply moves further away from you. At a certain point they are no longer engaged in representing patient's will, but rather in their own grief and mourning process, which then translates into conflicts or nasty threatening situations, lawsuits and so on. That is well, that is really terrible." FDP#4.* *"You can never meet the expectations of family, because you can never offer them what they want." FDRT2#1.*
	Personal and professional impact	Shortage of staff with PDOC expertise, psychological strain, inability to detach at home, doom-thinking resulting in overprotectiveness at home	*"Contact with family consumes a considerable amount of energy. Expectations, as they are often high, remain unfortunately unfulfilled. When you have to conduct many such conversations on a day, your energy reserves are quickly exhausted." FDRT1#9.* *"I also have to say that I could not do this work full time. […] If I should do it full time, mentally speaking, I do not know if I can handle that." FDN1#1.*

Table 3
Needs of Health Care Professionals

Theme: Category Need	Subthemes: Description of Requirements	Quotations
Improvement in working conditions	Stable team and sufficient personnel with PDOC expertise. Manageable workload. Improved work facilities.	*"Yes, I find it difficult. I realize that we are all working extremely hard to get things in place, but I find the group of people that it's happening with is a very small group, which is logical, but it's very vulnerable. [...] And if that is what the future holds, that you must get a grip on such a complex patient population with such a small group of people, so there should be more people." FDRT1#10.*
Psychological support for health care professionals	Structural psychological support and coaching. Healthy/safe working environment. Informal sharing moments and appreciation of colleagues and superiors. Structural discussions of complex cases and moral deliberation.	*"Precisely, those moments of professional discussion, that multidisciplinary fine-tuning with each other. [...] I believe that you have to maintain a constant dialogue with each other and that you can also back each other up if those (family) expectations are very high, so that you remain in harmony as a team. The team feeling is extremely important." FDRT2#1.*
Training and professional development	PDOC-specific (on-job) training. Learning skills to deal with unrealistic demands and inappropriate behavior of patients' families, resilience training.	*"Training can certainly be helpful, especially focused on how to collaborate with patients' family, even when the expectations are far apart." FDRT1#9.*
Better support for *patient's* family	Improved psychological guidance. Appointing case manager for practical support. Housing/accommodation facilities. Independent professional for guidance of decision-making process.	*"I think, we must somehow find a way to train those families, maybe in being a representative, because now we try and support them as much as possible to help them through their grief. But they still have a responsibility to fulfill in being a legal representative and that requires a whole different approach in my opinion. [...] Maybe there should be a completely different official for that." FDP#4.*
Improvement in care procedures	Clarity in prognosis and treatment protocols Care coordination after end of intensive neurorehabilitation within PDOC chain-of-care, optimizing triage criteria.	*"I still find it a challenge if they do regain consciousness, but ultimately cannot be rehabilitated further. Then they really fall between the cracks again. That is precisely what we first tried to prevent. As they are conscious, they cannot go to PIN, but they cannot go to a regular rehabilitation center either because they are too weak for that, but what then?" FDP#5.*

discuss various ideas to improve psychosocial support for families, such as providing easily accessible information on PDOC, structural psychological assistance, (temporary) housing facilities in the vicinity of rehabilitation centers to overcome transportation problems, and appointing a case manager to support the patient's family throughout the chain-of-care with practical and financial issues instead of individual social workers in different institutions. Physicians suggest assigning an independent official who can guide and help families to reconstruct patients' treatment preferences.

Continued Improvement of Care Procedures

Participants appeal for suitable rehabilitation facilities for patients who regain consciousness but do not fit in regular rehabilitation. EIN participants are particularly concerned about the current triage system and argue that omitting EIN and direct admission to PIN could be a better approach for older individuals who struggle with a high therapy intensity at EIN. Appropriate financial resources, long-term vision of stakeholders and employers regarding PDOC care, and willingness to invest in research and innovative technologies is seen as vital for improvement of care.

Discussion

This study explored experiences and needs of health care professionals working with PDOC patients and their families in post-acute and long-term care settings in a unique nationwide chain-of-care providing intensive neurorehabilitation up to 2 years post-injury.

Professionals describe their work as rewarding and challenging in unison. They feel privileged in providing complex yet meaningful care to the patients and supporting patients' families. They cherish collaborations within teams and the national care network while appreciating personal and professional enrichment due to their work. The confrontation with the condition of patients, families' grief, complex interaction with families, and dealing with moral distress have a negative impact on their personal and professional life. For sustainability, professionals need a stable team with a reassuring work environment. They particularly request psychological support and training to develop specialist skills that help them navigate through the challenges inherent to PDOC care, such as decision-making amidst prognostic uncertainty and supporting bereaved families while managing their unrealistic demands or aggressive behavior.

Our findings broadly corroborate prior research describing both positive and negative aspects of working with PDOC patients.[11,12,19] Building on previous single-center studies conducted in (hyper) acute settings, our multicenter study adds depth by comparing both similarities and disparities in the experiences and needs of professionals across various care settings, over an extended period post-onset. Unlike the difficulties experienced by professionals in "dealing with death and living death" in previous studies, professionals in our study, particularly those working in PIN, not only appreciate offering recovery opportunities but also perceive providing terminal care as meaningful and death as a relief for patients' suffering. This may be explained by the long-standing culture of palliative and terminal care in Dutch nursing homes.[31] Inappropriate behavior from patients' families is more frequently reported in PIN than in EIN. This may be attributed to the changes in treatment goals and fluctuating nature of hope during the PDOC trajectory. The shift in care goals from recovery-oriented rehabilitation to chronic care and end-of-life decisions in PIN, particularly when meaningful recovery is no longer anticipated, can be confronting for patients' families. The loss of long-held hope of recovery and the fear of losing their loved one may transform into mistrust and aggressive attitudes toward professionals in nursing homes. The influence of other factors, such as unmet family needs, the negative public perception of nursing homes, and increasing societal intolerance, requires further exploration. Given their role and close interaction with patients' families, nurses are adept at recognizing their psychological distress, but often face challenging behavior from families.[32] This explains their request for better family support and resilience training for staff. Strained relationships with families arising from communicating complex themes like downscaling of treatment or end-of-life issues respectively explains RTs' need for better communication skills and physicians' request for appointing an independent official to assist in reconstruction of a patient's will.

Strengths and Limitations

A high participation level of RTs and physicians and inclusion of various disciplines from both nursing homes and rehabilitation centers allowed us to draw valuable conclusions regarding experiences and needs of health care professionals working within PDOC chain-of-care. COVID-19 restrictions and staff shortages caused methodological and logistic issues like a lower participation rate of nurses and 1 online focus group potentially affecting the depth of participant response. The predominance of female participants, particularly nurses, may influence the generalizability of our findings as male participants may have different perceptions. Additional participation opportunities (more focus groups or interviews) and a more heterogeneous population could have enriched the data further. Because most nursing professionals are women, the participant composition is representative of the current workforce. Furthermore, a researcher working at PIN conducting one focus group may have influenced participant response. A nonjudgmental environment, confidentiality, and participant value were therefore emphasized. We also acknowledge the potential participation bias, as health care professionals experiencing burnout might have opted out. The insight of those suffering from burnout is crucial for a better understanding of the challenges of this demanding job. Additional interviews and written testimonies alongside focus groups enhanced validity of our results through data and source triangulation. Future research may incorporate recruitment strategies to prevent participation bias, such as providing support for mental health and well-being, and ensuring that the study design includes participants who are experiencing or have experienced burnout.

Conclusion and Implications

Our findings underscore the demanding yet rewarding nature of specialized post-acute neurorehabilitation and care for patients with PDOC and its impact on health care professionals. Health care professionals feel privileged in providing meaningful care to PDOC patients and supporting families through the intensive process but face staff shortages, moral distress, lack of job-specific training, and psychological support. A stable motivating team, regular moral case deliberations, psychological support, learning protective coping strategies, and specialized training are crucial in dealing with family expectations and moral distress. Despite differences in international health care systems, these findings provide valuable tools to enhance existing care programs, improve family support systems, develop PDOC-specific training (eg, improving communication skills, breaking bad news, self-efficacy, and learning de-escalation strategies), and inform organizational and policy reforms. A proactive stand from employers and policymakers is essential to ensure well-being and avoid turnover among highly qualified health care professionals involved in PDOC care. Fostering physical and psychological safety, a zero-tolerance policy, organizational de-escalation program, promoting public awareness including media attention, and enforcement of legislation can help ensure ownership and accountability. Facilitating these dedicated professionals by their employers within a learning expertise network is the key for sustainability of this indispensable care.

Availability of Data and Materials

The data that have been used are confidential and only available on a reasonable request.

Disclosure

The authors declare no conflicts of interest.

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Supplementary Data

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