‘Bad news in a good way’ – clinicians’ experiences of communicating the diagnosis and prognosis of prolonged disorder of consciousness (PDOC) to relatives: semi-structured interviews.

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Abstract

Background: Sensitive and effective communication is essential when delivering difficult information to families of people with prolonged disorders of consciousness (PDOC); however, clinician’s experiences and strategies to improve the experience are under-reported.

Aims: explore clinicians’ experiences of communicating difficult information to relatives of people with PDOC and their strategies to improve the experience for themselves and relatives.

Methods: Semi-structured online interviews with clinicians experienced in working with people with PDOC. Recorded data were transcribed verbatim and analysed using thematic analysis.

Findings: From eight interviews, themes were identified in two categories: experiences (responsibility, diagnostic uncertainty, and grief) and strategies (creating a shared understanding of PDOC and rehabilitation for PDOC patients, creating trust, and educational strategies).

Conclusion: Support for clinicians to facilitate optimal communication with relatives of people with PDOC remains under-explored but is a fertile area for further research with potential to reduce the emotional burden on clinicians and relatives.

Introduction

Prolonged disorder of consciousness (PDOC) is a state of wakefulness without awareness, or with minimal awareness of the person's environment lasting longer than four weeks following a sudden onset brain injury (Royal College of Physicians, 2020). Diagnosis of PDOC is by structured behavioural assessment by specialist multi-disciplinary team over at least three weeks (Royal College of Physicians, 2020), usually conducted in specialist neuro-rehabilitation units.

Family support for patients undergoing PDOC assessments is important (British Society of Rehabilitation Medicine (BSRM), 2019; Royal College of Physicians, 2020), as the impact of PDOC states on patients' relatives can be devastating (Wade, 2017; Chinner et al., 2021). Additionally, some patients exhibit responses to loved ones that are not replicated during clinician assessment, and some assessments specify that family observations be collected when diagnosing the level of the disordered consciousness (Tennant and Gill-Thwaites, 2017) to ensure that this variation is taken into consideration (Royal College of Physicians, 2020). However, for this to be viable, relatives need to have a good understanding of PDOC and a collaborative relationship with clinicians undertaking assessments. Furthermore, relatives are often asked to state patients' previous beliefs and wishes to be used as part of best-interest decisions regarding discharge destination and withdrawal of nutrition and hydration (BSRM, 2019; Royal College of Physicians, 2020). A clear understanding of the PDOC diagnosis and prognosis is vital for relatives to judge these perceived wishes accurately.

Whilst guidelines such as the SPIKES protocol (Buckman, 2005) help clinicians structure complex conversations delivering bad news in other areas of healthcare, there are currently no guidelines to help clinicians navigate communication with relatives of patients with PDOC, despite recognising that this cohort presents a unique set of challenges.

Most patients with PDOC are unlikely to survive their initial injury (Royal College of Physicians, 2020), so the journey from intensive care to acute ward and into rehabilitation often creates an expectation of miraculous recovery for families. This expectation is often supported by representations of coma in the media, which often show an ‘awakening’ to normal function, sometimes months or years after injury (Kitzinger, 2019). Admitting patients with PDOC to rehabilitation units raises expectations for families since rehabilitation is perceived as synonymous with functional recovery (Sexton, 2013). However, most patients with PDOC at six months post injury will not emerge from this state, and cases of late emergence invariably have significant and enduring neurological deficit (Wade, 2017; Kitzinger, 2019).

Relatives actively grieve the loss of the person they knew and loved throughout the patient’s healthcare journey (Kitzinger and Kitzinger, 2015; Chinner et al., 2021). Thus, conversations regarding diagnosis and prognosis are extremely emotionally charged, and relatives' ability to engage with and retain information is impaired (McCorry and Mason, 2020).

The Centre for the Disorder of Consciousness (CDOC) has conducted extensive research with relatives of patients with PDOC to explore their experiences of the healthcare journey and have created training to support clinicians to improve their communication with relatives based on this research. However, the experiences and strategies of clinicians working in this arena remains underarticulated in the literature. This study aims to bridge this gap through exploratory research addressing two research questions:

1. How do clinicians experience communication of diagnosis and prognosis with relatives for patients with PDOC?
2. What strategies have clinicians developed to improve the experience for themselves and the relatives?

Methods

Design: semi-structured interviews to explore lived experiences of healthcare professionals communicating difficult information to relatives of patients with PDOC, using a phenomenological approach within a constructivist paradigm.

Ethics: All procedures were performed in compliance with relevant laws and institutional guidelines and approved by the institutional committee.

Research team: The lead author is a clinical nurse specialist regularly engaged in communication with relatives of PDOC patients regarding diagnosis and prognosis. Her professional experiences of the complexity of these conversations, and the emotional toll they have, provided both the impetus to undertake this research, and the knowledge and experience required to collect and interpret the qualitative data.

Population and sampling

Using a purposive sampling strategy, qualified clinicians who communicate diagnosis or prognosis information with families of patients with PDOC on at least a monthly basis, and have been doing so for at least two years, were recruited. There were no specified exclusion criteria. Considering the specific nature of the topic and the experiences and characteristics of the participants in relation to the study aims, based on the concept of information power (Malterud et al., 2015) and on the recommendation of between 5-25 interviews for a phenomenological study (Creswell, 1998), this study aimed to recruit up to 10 participants.

Recruitment

Eligible volunteers were recruited following an invitation email and recruitment poster sent to specialist neurological nursing homes and non-NHS neurological rehabilitation facilities in the West Midlands, and a range of professional networks and groups: British Association of Neuroscience Nurses; UK Acquired Brain Injury Network; local research networks; UK Council for AHP Research (CAHPR) regional hub; regional Special Interest Group for Neurological Therapists (SIGNeT); and UK Society for Research in Rehabilitation (SRR). A participant information sheet was provided prior to gaining written consent, which was emailed back to the research team prior to the interview.

Interview process

A topic guide and interview questions were developed by the lead author (AS) based on her clinical experience and gaps in the existing literature regarding healthcare professionals' experiences of these conversations, and subsequently agreed with the research team. One pilot interview was conducted (Participant A), confirming the topic guide and questions ensured adequate depth of data following coding by two researchers. No changes to the interview guide or method of data collection were made.

Volunteers meeting eligibility criteria were invited by email to an online interview using Microsoft Teams, scheduled at a mutually convenient day and time, to last for up to one hour, conducted in English by the lead author (AS). Interviewer and participants were all located in private rooms, confirmed verbally by all participants prior to commencement of the interview to ensure confidentiality. Recognising that the subject matter could evoke strong emotions, participants were offered a debrief opportunity at any point following the interview, on request.

Data analysis

Interviews were recorded and auto transcribed, checked for accuracy and amended. Inductive thematic analysis was used to identify themes derived from the data, based on the stages recommended by Braun and Clarke (2006): familiarization, generating initial codes, searching for themes, reviewing the themes, defining and naming the themes.

Qualitative rigour

Steps were taken to increase rigor of the study, minimising the risk of bias and maximising trustworthiness (Nowell et al., 2017). The research topic was feasible, interesting novel, ethical and relevant (FINER), which is critical to rigor and quality (Johnson et al., 2020). Trustworthiness was achieved through triangulation of data analysis and theoretical saturation (O'Reilly and Parker, 2013), audit trails, rigorous data analysis, and reflexivity, which was recorded throughout the data analysis process. Two members of the research team shared data and analysis at key points throughout the research process, with codes and themes generated independently, and final themes identified and agreed following discussion. Audit trails of data collection and analysis were shared and retained to enhance confirmability.

Results and Discussion

Eight participants volunteered to be interviewed, all of whom met the inclusion criteria, and all eight completed the interview, giving a completion rate of 100%. Interview times ranged from 25 – 52 minutes.

Participants

Participants were recruited from two centres: one Level 1 neurorehabilitation unit and one neurological specialist nursing home. Participants are identified by letter e.g. P-A for participant A. Participants consisted of one doctor, one nurse, one physiotherapist, three occupational therapists and two speech and language therapists, who all had more than two years' experience working with patients in PDOC and their families.

Table 1: Participant's profession and place of work

Participant code	Participant's profession and place of work

P-A	Occupational Therapist, Level 1 neurological rehabilitation unit
P-B	Occupational Therapist, Level 1 neurological rehabilitation unit
P-C	Speech and Language Therapist, Level 1 neurological rehabilitation unit
P-D	Speech and Language Therapist, Level 1 neurological rehabilitation unit
P-E	Nurse, Level 1 neurological rehabilitation unit
P-F	Junior Doctor, Level 1 neurological rehabilitation unit
P-G	Physiotherapist, Level 1 neurological rehabilitation unit
P-H	Occupational Therapist, specialist neurological nursing home

Themes were identified for the two categories – clinical experiences (responsibility, diagnostic uncertainty, grief) and clinician strategies (achieving a shared understanding, creating trust and rapport, educational strategies) - summarised in Table 2.

Table 2: Summary of themes for the two categories: clinician experiences, and clinician strategies.

Category	**Themes**
Clinician experiences	Responsibility Diagnostic uncertainty Grief
Clinician strategies	Achieving a shared understanding Creating trust and rapport

	Educational strategies

Clinician experiences

Responsibility

Participants expressed their sense of responsibility for communicating PDOC diagnosis and prognosis to relatives in a way that did not add to their already considerable distress:

> *'It does feel like a burden, because it is, it's a massive thing to talk about and it's someone they love and it's telling them some information that they potentially don't want to hear [it] can be really upsetting.'* (P-A)
>
> *'It's a big responsibility and, you know, we all feel it if we don't...if we don't feel the conversation has landed well, you know, it really sticks with us, I think, as clinicians. And no doubt sticks with the family as well.'* (P-D)

Every interaction with relatives carried significant emotional weight, and one poorly worded or misjudged conversation could undo many months of relationship-building:

> *'I think you've got to do it right. You only sometimes get the opportunity to do it once really well.'* (P-A)
>
> *'You tread on eggshells a bit sometimes and I think one mis-worded sentence can throw them off the edge.'* (P-B)

Whilst accepting this responsibility as an integral part of their job role as experienced clinicians, they acknowledged that they had found this very challenging when in more junior roles:

> *'I think it was a job that I used to dread because nobody likes giving bad news and I think we want to be the people that want to give good news…I think now I don't mind having them.'* (P-C)

However, participants expressed a desire for concrete communication guidance as well as more structured supervision, practice and support:

> *'It's not anything I ever had training on…But it's not anything we're taught and I think, you know, we don't even get opportunities to role-play. Like, I hate role-play, but we never even get opportunities to do any of that stuff. You know, we do on mandatory training and then we're thrown in at the ward level going into like key-working, we're not really giving much training on key-working and then we're put in an initial goal-planning meeting with a family who are in the worst case scenario for them, and we're the ones who are sort of looked at* [to] *chair those conversations.'* (P-D)

The responsibility on clinicians to deliver *'good news in a bad way'* (P-A) is vital for ensuring robust assessments and best-interest decisions that reflect patient's previous beliefs and wishes (Royal College of Physicians, 2020). Communication breakdown between relatives and clinicians can lead to increased psychological morbidity for relatives (Wade, 2017; Chinner et al., 2021), and clinician burnout (Peel et al., 2020). Notably absent from the literature is advice and support for clinicians on how to best approach these conversations;

CDOC (2022a) helps clinicians understand and avoid pitfalls of poor communication, and how this can impact relatives' understanding and trust in healthcare.

The desire for more structured guidance, supervision and support marries with the assertion that lack of training and guidelines for breaking bad news in neurological rehabilitation can lead to increased staff stress and avoidance of difficult conversations (Peel et al., 2020).

Diagnostic uncertainty

The uncertainty inherent in diagnosis and prognosis of PDOC impacts communication with relatives; many participants cited examples where they subjectively felt there was greater awareness present than demonstrated in formal objective assessment:

> *'I currently on my caseload have another person who feels like he's emerged. He really, really does. He doesn't meet the criteria. But he feels it…he gives you looks when you're doing the assessments...that say 'I know what you're doing. And this is boring'.'* (P-H)

> *'There's nothing scientific. You just get a feeling they're there.'* (P-A)

Requirement for a motor response witnessed by a validated assessor was felt to add to uncertainty regarding PDOC diagnosis:

> *'One of the downfalls of the SMART assessment is you need a motor response. There are so many things in brain injury that could stop a cognisant person giving a motor response.'* (P-G)

> *'Family can say they've seen it, which is really horrible, really. But until a trained assessor has seen it and validated it, then it's not sort of counted. So I'll try and give them support with that.'* (P-A)

There was added complexity in clinicians recognising their own emotional engagement with patients, making interpretation of motor responses challenging:

> *'It's difficult because they* [relatives] *so want to see something, and we so want to see something. That is a challenge in itself. Like, er, did they do that?'* (P-E).

> *'If some-one* [a relative] *is saying they're seeing it, they may be seeing it and, and I think I will will things to happen, and think I am seeing this and I'll bring a colleague along because I realise I really want this person to do it.'* (P-A).

Discussing late emergence with relatives provided challenges due to the perceived need to balance honesty with avoiding false hope:

> *'I don't start talking about…the man I worked with once, who is now up and walking but equally…it's really hard not to.'* (P-D)

> *'It's few and far between, but it has happened that we've started a SMART and they are VS…and then you come in one morning and they're like 'What's happened?' But how do you explain that?'* (P-B)

> *'I'll say sometimes things can get better, but you really have to stress that is rare…It's a challenge.'* (P-F)

Findings of this study contrast with the assertion that clinicians are primed to put significant faith in behavioural assessment outcomes (Edgar et al., 2014), and these myriads of complexities mean it is unsurprising that discussions of diagnostic and prognostic uncertainty with relatives are often not straightforward, and cause trepidation amongst clinicians.

Relatives' optimism, lack of experience of reflexive movements, and the innate social context of their interactions with the patient, can lead to them overestimating the patients' level of awareness (Nettleton et al., 2014; Royal College of Physicians, 2020). Consequently, there is good clinical sense in limiting the impact relatives' observations have in deciding PDOC diagnosis, to avoid instilling false hope through misinterpretation of reflexive movements (Kitzinger, 2019; Royal College of Physicians, 2020; Chinner et al., 2021). However, this must be balanced with the recognition that many patients with PDOC respond best to loved ones, and that relatives may be best attuned to volitional responses as they are the only member of the care team to have known the patient in a full state of consciousness (Latchem and Kitzinger, 2015). Achieving this balance in practice was recognised to be extremely challenging, and further complicated by the need to avoid paternalism, a key cause of communication breakdown between relatives and clinicians (CDOC, 2022b).

Grief

Clinicians experience a range of relatives' emotions, including hope often bordering on denial, anger, bargaining and guilt:

> *'I think a large part of our job, I think, is making sure they're supported from a grieving point of view.'* (P-B)

> *'A lot of us feel we are helping to manage some-one's grieving process really, because the person they knew isn't there anymore.'* (P-C)

Participants acknowledged grieving as a normal response, and accepted that blame and anger may be directed towards them when communicating outcomes of PDOC assessments:

> *'That's their grief, and I think that encompasses a hell of a lot. What they wanna hear and how they perceive what's being heard.'* (P-B)

> *'It's about being really sensitive to how they're feeling and, you know, as a team on the ward, you do get a lot of unjust criticism…but I think as a professional, it's* [our job] *to acknowledge that's their grief at the moment.'* (P-B)

Some participants felt that guiding relatives towards acceptance was part of their job, whereas others felt their role was more to bear witness to the relatives' emotions:

> *'We offer support, like psychology, and Headway, to help them come to terms with what's happening.'* (P-B)

> *'Sometimes it is just a case of acknowledging, actually. It's kind of alright for the loved ones to feel like that because it is, for want of a better word, just pretty shit.'* (P-D)

> *‘Sometimes they come into you saying ‘He just shook his ‘head’ and they just want you to go ‘I’m so pleased you saw that’.’* (P-G)

All participants articulated a degree of vicarious grief when working with PDOC patients causing a risk of burnout:

> *‘They’re grieving in front of you and they’re aware of that as well...and it’s just so traumatizing.’* (P-H).

> *‘Those conversations are just as difficult as the ones that I had as a Band 5 just because it’s so heartbreaking.’* (P-D)

> *‘There’ll be some stories you can detach from but there’ll be others that will just break your heart.’* (P-B)

Some clinicians managed this by maintaining a level of professional distance, whereas others appeared to lean into these emotions and use them as a vehicle to build compassionate relationships with families:

> *‘I think you have to stay emotionally removed from it…we’re not there to fall apart on the families. The families need us to be there and be that stable base, a stable continuity even if it’s not what they want to hear.’* (P-G).

> *‘In some ways, it’s easier now I have kids, coz I can say ‘if that were my child I would feel exactly how you are feeling’.’* (P-D)

Relatives' emotional responses correspond to the Kubler-Ross and Kessler (2014) cycle of grief, and the prevalence and strength of emotions supports research reporting that 61% of relatives of PDOC patients would meet the criteria for a diagnosis of complex grief disorder (Chinner et al., 2021). In contrast to this study, Kitzinger and Kitzinger (2015) found that relatives felt their grief was often pathologized by clinicians. Psychological support should be available, and access to this should be guided by relatives' wishes (Royal College of Physicians, 2020).

There is no available literature reporting emotional impacts on clinicians working with patients with PDOC, but the range of responses and the poignant descriptions by participants in this study strongly indicate that increased support for managing these effects would be beneficial for staff wellbeing.

Clinicians' strategies

Achieving a shared understanding

Many strategies identified by participants involved achieving a common understanding of the meaning of PDOC and rehabilitation in this context, widely acknowledged to be due to relatives' and clinicians' expectations starting from different points:

> *'Families come to the rehab unit and think 'Oh, they're gonna get physio, they're gonna get them standing, they're gonna get walking' and actually I'm having to explain from scratch the nature of physio with a PDOC patient.'* (P-G)

Some differences in expectations were attributed to the layperson's perception of rehabilitation being synonymous with functional recovery, and others due to experiences in the acute sector meaning information thus far had not been taken on board:

> *'They think they just need to sit more. You need to get them up more. And you know, then they'll be able to stand and walk…And it makes perfect sense – the more you do something, the better you get at it, right?'* (P-G)

> *'And it's a situation where that information just hasn't been shared from the acute service. Or they've not heard it, most likely it has been said, if I'm really honest, because I do believe that people are saying these things, probably not in the same terms as we might do, but I just don't know if they hear it. They hear that they're alive, they're fine. And we're referring to rehab.'* (P-A)

The process of 'drip-feeding' information to relatives was highlighted, whereby all members of the treating team would revisit information on multiple occasions, both formally in best-interest meetings and informally during visits or phone calls; this was vital to gaining a shared understanding of the goals of rehabilitation:

> *'They* [families] *are really, really hopeful wonderful things are going to happen. Then I just quietly drip-feed that same information that, you know, we haven't seen any responses. We haven't seen any responses. It's often suggested that if a patient is in a PDOC for X amount of time, it's unlikely it's going to change.'* (P-G)

> *'It's too much to do in one meeting – can't do it and it's not fair…I spend hours and hours going over it across the person's stay'*. (P-A)

> *‘These relatives often want a lot of your time…and I think my fallback is to get one of the more senior doctors or senior nurses to also speak to them.’* (P-F)

Challenges to an effective delivery of drip-feeding included a lack of recognition of the importance of informal discussion, with no ringfenced time to achieve this, and challenges in ensuring consistent messaging across the MDT, particularly with its most junior members:

> *‘Don’t want to spend so much time with them that it ends up impacting the amount of time I’m with the patient. It’s as if there’s something missing in the middle there.’* (P-B)

> *‘I think we have training on care, trachy, GAS goals etc…but we don’t have training on this, and we have plenty of band six starters…and no doubt from your perspective with care staff, you must also have tons of HCAs and nurses who come in and have never met someone in a PDOC before.’* (P-D)

Furthermore, using words such as ‘rehabilitation’ were widely acknowledged to be unhelpful in creating a shared understanding of PDOC and the likely outcomes:

> *‘There’s something about the rehab word. I think it’s really tricky for these patients ‘cause you know, whilst it’s totally appropriate for PDOC patients to come to Level 1 rehab settings, the very fact that rehab is in there…the message can feel like they’ll go to rehab so they can recover.’* (P-D)

Misleading language can damage families’ faith in the multi-disciplinary team and instil false hope (CDOC, 2022c). A greater cascade of training into practice, and a reimagining of vocabulary regarding inpatient disability management and PDOC assessment could be useful in improving this process.

Formal best-interest and review meetings should be the key method for information-sharing with the relatives of patients with PDOC (Royal College of Physicians, 2020). Regular, informal discussions are also essential to supporting relatives in their understanding of diagnosis and prognosis, with ‘drip-feeding’ recognised as a key strategy in helping patients and relatives understand prognosis in functional neurorehabilitation (Peel et al., 2020; Sexton et al., 2013), giving relatives the information at the pace that was correct for them. Although not currently clearly articulated in other PDOC literature, data from this study suggests this was standard practice across the units where these participants worked. An improved recognition of drip-feeding as an essential principle of communication with relatives could help to alleviate staff stress by ringfencing time for it, and allowing more formalised co-ordination of the process to improve its efficacy.

Creating trust and rapport

Creating a trusting relationship with relatives was widely articulated to be important in enabling effective communication regarding PDOC diagnosis and prognosis:

> *‘You’re gaining their trust because* [without it] *they literally switch off…because you’re some-one who’s negative and you’re telling them things they don’t want to hear.’* (P-C)

> *'We need them to have some level of trust, but we have to work for that trust as well.'* (P-C)

Honesty was identified as a key strategy in forging these relationships; relatives appeared to respect honest, difficult responses even if these did not align with their hopes and expectations:

> *'I try to do things in a way that's very truthful, very factual, very soft but without holding back really, because the worst thing is not to say the truth.'* (P-A)

> *'You know, actually, it's OK to admit defeat. I think relatives respect that, if you don't know it rather than, you know, trying to, pardon my French, BS them…Rather than constantly trying to backtrack or cover up…you know, just tell them the truth. I think that's what's acknowledged the most actually. Tell them you've tried something and it hasn't worked. I think that ownership of what you're doing with their loved one is really important.'* (P-B)

Another key strategy for building trusting relationships was acknowledging the personhood of the patient:

> *'No two patients in PDOC are going to present the same and they will all have their own families and their own stories and everything that goes with that.'* (P-C)

'We talk a lot about the people they were. How they lived. What they did.' (P-A)

Honouring relatives' experiences and knowledge of the patient was an important strategy for building trust, and participants considered this process to occur best in informal settings:

> '[Relatives are] *the experts in different bits. Actually, experts in that person.'* (P-C)
>
> *'I usually find the more I let them talk, the more I get out of them in terms of what they've seen from their relative…I use that on an informal level to gauge where that relative and that PDOC patient is at.'* (P-B)
>
> *'I tend to go into more detail and get through more outside of the meetings – 'cause it's just too much and quite intimidating sometimes in there with all those people talking at you.'* (P-A)

This further adds to the suggestion that a greater recognition of the importance of informal communication with relatives, and recognition of the resources required to make this successful would be highly beneficial.

Acknowledging personhood is important for building good relationships in long term neurological care (Latchem and Kitzinger, 2015). However, personhood is synonymous with consciousness (Nettleton et al., 2014); therefore, recognising the patient's personhood whilst simultaneously helping relatives understand the meaning of PDOC could create tensions in practice. Further guidance for clinicians on how to manage this balance may be advantageous in improving trust between clinicians and relatives.

Educational Strategies

Some common educational strategies included joint therapy sessions with relatives, which was felt to highlight patient progress (or lack of) better than discussion, and the use of technology to enable reinforcement of key points*:*

> *'So we, you often end up having to do quite a lot of joint sessions with them* [families] *so that they can see. So I find it useful to have family members in there from day dot really so they can see we have been trying for 12 weeks and nothing has changed.'* (P-G)

> *'I would give them an example for if I asked them to move their head – Yes, they might do that at rest, but am I seeing that they can consistently do that when I ask them to do it? And sometimes that kind of explanation, it's almost a bit of a light bulb moment* [for family members]*.'* (P-B)

> *'Recently I've used a lot of apps on my phone to actually have those discussions again and again and, and I think it seems to be quite repetitive and they needed to be having several times rather than one off and that's it, because I think the information they* [are] *able to process and retain is very different for different families.'* (P-C)

Family support groups were identified as methods to support relatives' understanding of diagnosis and prognosis:

> *'It would be lovely to think that if we had the resources we could put together some sort of support system for families. You know, a coffee morning, or a course or some sort of forum for them to properly meet each other.'* (P-D)

> *'If there was a support group we could set up…and obviously we could tailor it depending on the nature of the relatives coming in. I do feel something is lacking, and I don't quite know how to fix that.'* (P-B)

Royal College of Physicians (2020) recommends family involvement in therapy sessions and PDOC assessments, but there is currently no research on how technology could help communication with relatives of patients in PDOC, so this may warrant further exploration.

Wellbeing of relatives of patients in PDOC can be improved by group psychological therapy (Corello et al., 2015), and a link has been established between caregiver stress and communication difficulties between relatives and clinicians (McCorry and Mason, 2017). This suggests relative's understanding of PDOC could be improved by family support groups by virtue of their improved psychological wellbeing making them more able to take on board the information offered; however, this should be robustly evaluated in practice given the paucity of available literature.

There are currently no studies evidencing how family support groups help relatives to understand diagnosis and prognosis in PDOC, although this was an idea that featured frequently in this study.

Limitations

Whilst the sample size of eight participants may be considered small and insufficient to reach data saturation in a heterogenous sample (O'Reilly and Parker, 2013), the findings of this study offer novel insights into the experiences of healthcare professionals when communicating difficult information about diagnosis and prognosis to relatives of patients in PDOC. However, most participants were from a rehabilitation setting. Further studies would benefit from greater diversity of recruitment, including participants from the hyperacute sector.

Scope for further research

This study found that the amount of work involved in communicating with relatives of patients with PDOC is underestimated, and research to further quantify this workload and allow it to be planned effectively would enhance the experience for clinicians and relatives. Furthermore, the emotional impact on staff from working with patients with PDOC and their relatives is clearly underestimated, and further exploration on how to adequately support staff in these roles to avoid burnout would be highly beneficial. There is high demand from clinicians for more bespoke training or guidelines on how to approach discussions with relatives of patients with PDOC, similar to the SPIKES guidance (Buckman, 2005) for breaking bad news in healthcare. Although the effort required to provide an evidence base for these guidelines would be significant, this study suggests that this effort would be more than justified in the potential benefits to staff and relatives.

Conclusion

Experienced clinicians working with patients with PDOC and their relatives experience a significant burden of responsibility to communicate the meaning of the PDOC diagnosis and prognosis in the most compassionate way possible. Contrary to some literature on this topic, it was found that the diagnostic uncertainty inherent within PDOC was felt to not only complicate communication with relatives, but also created ambivalence within the participants as they were starkly aware of the limitations of behavioural assessments and the biomedical understanding of consciousness. Clinicians experience some level of vicarious grief and felt under-supported with the emotional demands of the cohort. Despite this, the participants had developed many strategies to help make communication with relatives of their patients with PDOC as effective as possible. These largely rotated around ‘softer skills’ such as relationship building although concrete educational strategies such as joint therapy sessions with relatives and use of technology were also identified. Further research with the aim of creating structured communication guidelines for this cohort would be welcomed by clinicians as they currently feel expectation management is given insufficient priority in regard to training or clinical time allocation.

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Key points

- Clinicians view communicating with relatives of patients in PDOC to be an integral and challenging part of their role.
- They experience a significant burden of responsibility to try and make communication as compassionate as possible, and a degree of vicarious grief regarding their work.
- Challenges to effective communication include the emotionally charged nature of the situation, the diagnostic uncertainty inherent within the cohort and the misperception created by the layperson expectation of rehabilitation.
- Strategies to enable effective communication include regular drip feeding of information in both formal and informal settings, and by multiple members of the multi-disciplinary

team, building meaningful trusting relationships between clinicians and relatives and joint working between relatives and therapists.

- Clinicians feel that there is insufficient training and resource allocation to enable this aspect of their job to be done optimally.

Reflective Questions

- What have you learnt about how other clinicians perceive and approach communication with relatives of PDOC patients?
- How does this compare to your own experiences and strategies?
- How might you adapt your own practice to take into account this learning?
- What might help you as a clinician feel more supported within this aspect of your role?

References

Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2);77-101. https://doi.org/10.1191/1478088706qp063oa

British Society of Rehabilitation Medicine. Specialist neuro-rehabilitation services: providing for patients with complex rehabilitation needs. 2023. https://www.bsprm.org.uk/resources/guideline-documents/ [Accessed 03/05/2024]

Buckman, R. ‘Breaking bad news: Why is it still so difficult?’ BMJ (Clin Res Ed). 1984;288(6430);1597–1599.

CDOCa. Communicating with Families – Module 3 – Research with families. 2022. https://cdoctraining.org.uk/module-3/research-with-families/ [Accessed 25/09/2023].

CDOCb. Communicating with Families – Module 4 – Therapists' reflections. 2022. https://cdoctraining.org.uk/module-4/therapists-reflections/ [Accessed 25/09/2023].

CDOCc. Communicating with Families – Module 4 – Hopes and expectations. 2022. https://cdoctraining.org.uk/module-4/hopes-expectations/ [Accessed 25/09/2023].

Chinner A, Pauli R, Cruse D. The impact on prolonged disorder of consciousness on family caregivers' quality of life: a scoping review.' Neuropsychol Rehabil. 2022;32(7);1643-1666.

Corello F, Bonnanno L, De Salvo S, Georgio A, Rifici C, Lo Bueno V, Bramanti P, Marino S. Effects of counselling on psychological measures in caregivers of patients with disorders of consciousness. Am J Health Behav. 2015;39(6);772–778.

Creswell, J.W. Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage. 1998.

Edgar A, Kitzinger C, Kitzinger J. Interpreting chronic disorders of consciousness: medical science and family experience. J Eval Clin Pract. 2015;21(3);374–379.

The Dipex Charity. Taking In Information and Imagined Outcomes. 2017. https://healthtalk.org/experiences/family-experiences-vegetative-and-minimally-conscious-states/taking-in-information-and-imagining-outcomes/ [Accessed 13/12/2022].

Johnson JL, Adkins D, Chauvin S. A review of the quality indicators of rigor in qualitative research. Am J Pharm Educ, 2020;84(1);7120. https://doi.org/10.5688%2Fajpe7120

Kitzinger, J. Can you wake up after decades in a coma? The story behind the headlines. The Conversation. May 2019. https://theconversation.com/can-you-wake-up-after-decades-in-a-coma-the-story-behind-the-headlines-116192 [Accessed 01/02/2024]

Kitzinger, C and Kitzinger, J. Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising. Clin Rehab. 2014;28(7);627–631.

Kubler–Ross, E, Kessler, D. On grief and grieving: finding the meaning of grief through the five stages of loss. London: Simon & Schushter UK Ltd. 2014.

Latchem J, Kitzinger J. Breaking down barriers – the importance of good relationships. Nurs Res Care. 2014;17(1);30–33.

Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res. 2015;26(13);1753-1760

McCorry L, Mason J. Communication skills for the healthcare professional – enhanced edition. Boston: Jones and Barrett Learning Publications; 2nd edition. 2020

Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. Int J Qual Methods. 2017;16(1) https://doi.org/10.1177/1609406917733847Nowe

Nettleton S, Kitzinger C, Kitzinger J. A diagnostic illusory? The case of distinguishing between 'vegetative' and 'minimally conscious' states.' Soc Sci Med. 2014;116(100);134–141.

O'Reilly M, Parker N. Unsatisfactory saturation: a critical exploration of the notion of saturated sample sizes in qualitative research. Qual Res. 2013;1*3*(2);190–197.

Peel R, Jones S, Miller C, Gibson J. Great expectations? A qualitative study of health professionals' perspectives on breaking bad news about rehabilitation potential after traumatic brain injury or spinal injury. Disabil Rehabil. 2020;42(22);3209–3214.

Royal College of Physicians. Prolonged disorders of consciousness following sudden-onset brain injury: national clinical guidelines. London: Royal College of Physicians; 2020.

Sexton, D. 'As good as it's going to get'. Bad news conversations in neurology: challenges for occupational therapists. BJOT. 2013;76(6);270–279.

Tennant A, Gill-Thwaites H. A study of the internal construct and predictive validity of the SMART assessment for emergence from vegetative state. Brain Inj. 2017;31(2);185–192.

Wade DT. Using best interests meetings for people in a prolonged disorder of consciousness to improve clinical and ethical management. J Med Ethics. 2018;44(5);336–