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Experiences and views of conversations about recovery and prognosis on the stroke unit: findings from semistructured interviews with professionals

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ABSTRACT

Objectives Providing information about the process of poststroke recovery, and individuals' likely outlook can be challenging for professionals, which may lead to avoidance of this important issue, leaving patients' and carers' needs unmet in relation to understanding their recovery. We aimed to understand professionals' experiences and views of providing information about recovery in stroke units.
Design Semistructured interviews were conducted as part of a wider ethnographic case study. A Framework approach to analysis was employed.
Setting Two UK stroke units.
Participants 19 qualified stroke unit professionals with a range of experience levels participated, including doctors, physiotherapists, occupational therapists, speech and language therapists and a nurse.
Results Three themes and seven subthemes were generated. Participants across disciplines perceived that discussing recovery could have important benefits, although many lacked guidance about their roles in this domain. Skills in predicting recovery and sharing these predictions were learnt experientially, and therapists reported a lack of preparatory training and confidence, resulting in perceptions of mixed experiences for patients. Many professionals were worried about the consequences of sharing personalised predictions, including the impact on patients' hope and motivation, and their ability to manage patients' and families' emotional responses. These concerns could result in professionals experiencing negative psychological consequences, for which limited formal support was available.
Conclusions Stroke unit professionals perceive that providing information about recovery, including individualised predictions, to patients and carers has important benefits; however, they require additional guidance, support and training to confidently engage in this important area of clinical practice.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Semistructured interviews facilitated detailed exploration and understanding of the views and experiences of professionals involved in conversations about poststroke recovery and prognosis.
- ⇒ Nurses were under-represented in the sample, and their role requires further investigation.
- ⇒ The study was conducted in two stroke units in a single UK region, thus the transferability of findings to other (international) contexts remains unclear.

INTRODUCTION

Formulating predictions about prognosis and sharing them with patients is a challenging and often uncomfortable task for clinicians, requiring enhanced clinical skills.[1] Research on communicating prognosis has tended to focus on formal interactions between a single clinician (usually a doctor) and a patient, typically within the context of a life-limiting disease, such as cancer.[2 3] However, it is increasingly recognised that a wide range of professionals may be involved in these discussions, including nurses and allied health professionals, and that conversations take place across a range of clinical areas.[2 4–6]

Predicting recovery after stroke presents particular challenges for clinicians as the recovery trajectory is often uncertain.[7] Affecting more than 12 million people every year,[8] stroke can have a wide range of effects, both physical and psychological.[9 10] Unlike life-limiting conditions, where the focus is typically on life expectancy and symptom management, conversations about prognosis following a stroke often have a positive element, as some recovery is nearly always possible. The focus is on the likely timing and extent of functional improvement, the process by which this recovery occurs and how recovery can be facilitated. These interactions typically begin on the stroke unit, where ~80% of patients spend most of their hospital stay.[11] Stroke unit care is provided by a multidisciplinary team (MDT), including doctors, nurses and therapists (primarily physiotherapists (PTs), occupational therapists (OTs) and speech and language therapists (SLTs)),[12] who may each contribute to providing information about likely recovery to patients and families. As many stroke survivors experience ongoing disability (around a third require help with activities of daily living at the point of discharge),[13] this may need to include discussions about the functional changes that may impair the person to perform personal care and social role activities; thus requiring professionals to break bad news. Therapists and nurses, however, receive little training in this area and can find these conversations challenging, particularly when they occur during rehabilitation, a setting in which there is a significant focus on preserving hope and encouraging full participation in therapeutic interventions in order to achieve the best outcomes.[14–17]

Understanding poststroke recovery is important to patients and their families; evidence suggests that receiving information about their likely recovery may facilitate involvement in shared decision-making,[18] such as around postdischarge care, and support adjustment to any continuing difficulties.[19 20] Providing information about recovery to patients is thus recognised as an important element of care within national stroke guidelines.[21] Research, however, frequently highlights patients and carers' dissatisfaction with the information provided.[22] There is also evidence that professionals may avoid the topic or provide vague information due to the challenges.[7 23 24]

Understanding professionals' experiences and views of providing information about the process of recovery and individual prognosis is key to ensuring they feel able to engage in conversations. Exploration of professionals' experiences to date has tended to focus on the views and experiences of single professional groups, for example, PTs,[17] or SLTs.[24] The multidisciplinary nature of stroke care, however, renders it unlikely that information about prognosis is provided to patients by a single professional; instead, the team must work together if they are to deliver a holistic approach. Few studies have explored how professionals experience working as part of a MDT to provide information about recovery in the stroke unit setting. To further investigate this issue, we conducted a focused ethnographic case study aiming to explore conversations about recovery in stroke units (including how information about likely outlook and the process of recovery is shared by staff and understood by patients and their families), using non-participant observations, interviews with professionals, patients, and carers, and documentary analysis. In this paper, we report findings from interviews with professionals, which aimed to understand their experiences and views of providing information about recovery to patients and their families within the context of stroke unit MDT working (the experiences of patients and carers are reported separately).

METHODS

Methods are reported in accordance with the Standards for Reporting Qualitative Research.[25]

Data were collected between June and October 2019 as part of the lead author's (L-JB) doctoral studies. Participants were qualified professionals recruited from two UK-based in-patient stroke units providing rehabilitation. Sites were purposively selected due to their divergent approaches in providing information about recovery, following conversations with senior professionals at three sites about their processes and approach (further information provided in the results). No authors had existing roles at any site.

Participants were purposively and heterogeneously sampled from those recruited to the wider ethnographic study, to explore experiences and views across disciplines and experience levels. Demographic data (gender, age, ethnicity, profession and experience level, years of experience in stroke) were collected at recruitment. Semi-structured interviews were employed to gain insight into how participants interpreted their experiences of conversations about recovery and capture their thoughts, feelings and beliefs.[26] Interviews were conducted following completion of non-participant observations at each site so as not to influence behaviour; most were conducted face to face in a quiet room at the hospital where the participant worked, and one took place via telephone. A flexible topic guide was developed (available at https://osf.io/2n3vd/files/osfstorage/65fc9fc999b3460180aa2d32), which included questions relating to participants' roles and current practice in providing information about recovery; how predictions about prognosis were made and communicated to patients and families; perceived effects and benefits of, and barriers to, provision; and staff support and training. Interviews were conducted by a female PhD student with experience in qualitative research who was unknown to participants prior to the study (L-JB). She kept a reflexive diary throughout the study, exploring and addressing potential biases and how these may have impacted questioning and interpretation, which she also discussed with coauthors throughout the study. Interviews were audio recorded and transcribed verbatim.

Data were managed in NVivo, with a Framework approach to analysis undertaken.[27] This five-stage method involves initial familiarisation with the data, followed by identification of a thematic framework. Framework analysis was selected for this study, as it provides a structured and transparent method of managing, and systematically and rigorously interrogating, large amounts of data, while facilitating within-case and between-case analysis; in this case between participants of different professions, of varying levels of seniority and from different sites.[26 28] In this study, we employed a thematic framework, which was initially developed through inductive line-by-line coding of articles included in a systematic review exploring the experiences and views of people involved in providing and receiving information about recovery in acquired neurological conditions.[14] The framework was further developed using an iterative process during the familiarisation stage (a combined deductive and inductive approach) by L-JB. During a third stage of indexing, L-JB coded the data according to the framework with code descriptions expanded and new codes added where needed, to capture all data relevant to the study objective (the final codebook is available at https://osf.io/2n3vd/files/osfstorage/6601e3b9b3a1e3000e7df10f). In a fourth stage of charting, data were displayed within matrices, and summaries of participants' views on each code were developed, staying as close to the original text as possible. Finally, participants' views and experiences were compared and contrasted in an interpretation stage, developing overall summaries for each code and examining them for areas of commonality and difference. Throughout the analysis process, analytical memos were developed to capture emerging insights, concepts or issues. Emerging findings were discussed across the research team, prior to the development of agreed themes. Alongside employment of reflexivity, these discussions functioned to enhance the validity of the findings by helping to account for potential researcher bias that could have impacted interpretations of the data.

Patient and public involvement

Ideas for this study were discussed with stroke survivors and carers from two community-based stroke groups in Greater Manchester and the Consumer Research Advisory Group (Leeds), who commented on the importance of the research topic and made suggestions for the recruitment and participation of patients and carers in the wider study (including reviewing recruitment materials and topic guides). The lead researcher visited each group, provided a short verbal presentation to introduce the topic and proceeded to have informal conversations with individuals and small groups to gather the views of a wide range of people.

RESULTS

The study context included two stroke units in one English county. Site 1 was a 35-bed stroke/neurology ward providing hyperacute, acute and rehabilitation services with an average length of stay ~6 weeks. Site 1 did not employ a co-ordinated team approach to the provision of information about recovery, which meant the topic was infrequently discussed with patients and carers, and few personalised predictions about the likely timing and extent were provided. Family meetings (employed by some stroke units to allow individual patients and their families to meet with their treating team to discuss their symptoms, treatment plans, progress and prognosis) were not routinely held. Where they were employed, they were held reactively and for a minority of patients, in response to challenges, for example, factors influencing therapeutic participation such as reduced engagement or pain, or the need for decision-making about treatment or discharge.

Table 1 Participants' demographic data (N=19)

	N	%
Gender		
Male	4	21
Female	15	79
Ethnicity		
White	17	89
Asian or Asian British	2	11
Mean (SD) age (years)	31.47 (7.83)	
Professional background		
Physiotherapist	6	32
Occupational therapist	6	32
Speech and language therapist	4	21
Nurse	1	5
Doctor	2	11
Experience level		
Junior therapist/nurse	6	32
Experienced therapist/nurse	8	42
Senior therapist/nurse or consultant	5	26
Experience in stroke care		
<1 year	4	21
1–5 years	10	53
6–10 years	1	5
>10 years	4	21

Site 2 was a 12-bed rehabilitation ward, located within a wider stroke unit comprising a hyperacute/acute ward and two additional rehabilitation wards. The average length of stay was ~3 months. In contrast with site 1, an agreed approach to sharing predictions about individuals' recovery outlook at site 2 meant information was proactively and consistently offered to patients and families at routine and regular family meetings.

19 professionals were interviewed (9 from site 1 and 10 from site 2; see table 1); most were white (n=17; 89.5%) and female (n=15; 79%). Participants represented those from a range of disciplines, including PTs (n=6; 31.6%), OTs (n=6; 31.6%), SLTs (n=4; 21.1%), doctors (n=2; 10.5%) and a nurse (n=1; 5.3%). Participants included those from a range of experience levels, including junior (National Health Service (NHS) Agenda for Change band 5 (n=6; 31.6%)), experienced (band 6 (n=8; 42.1%)) and senior (band 7 or above, or consultant (n=5; 26.3%)). Around half had between 1 and 5 years of stroke experience (n=10; 53%); around a fifth had less than 1 year (n=4; 21%) and more than 10 years (n=4; 21%). The remaining participant had between 6 and 10 years of stroke experience (n=1; 5.3%).

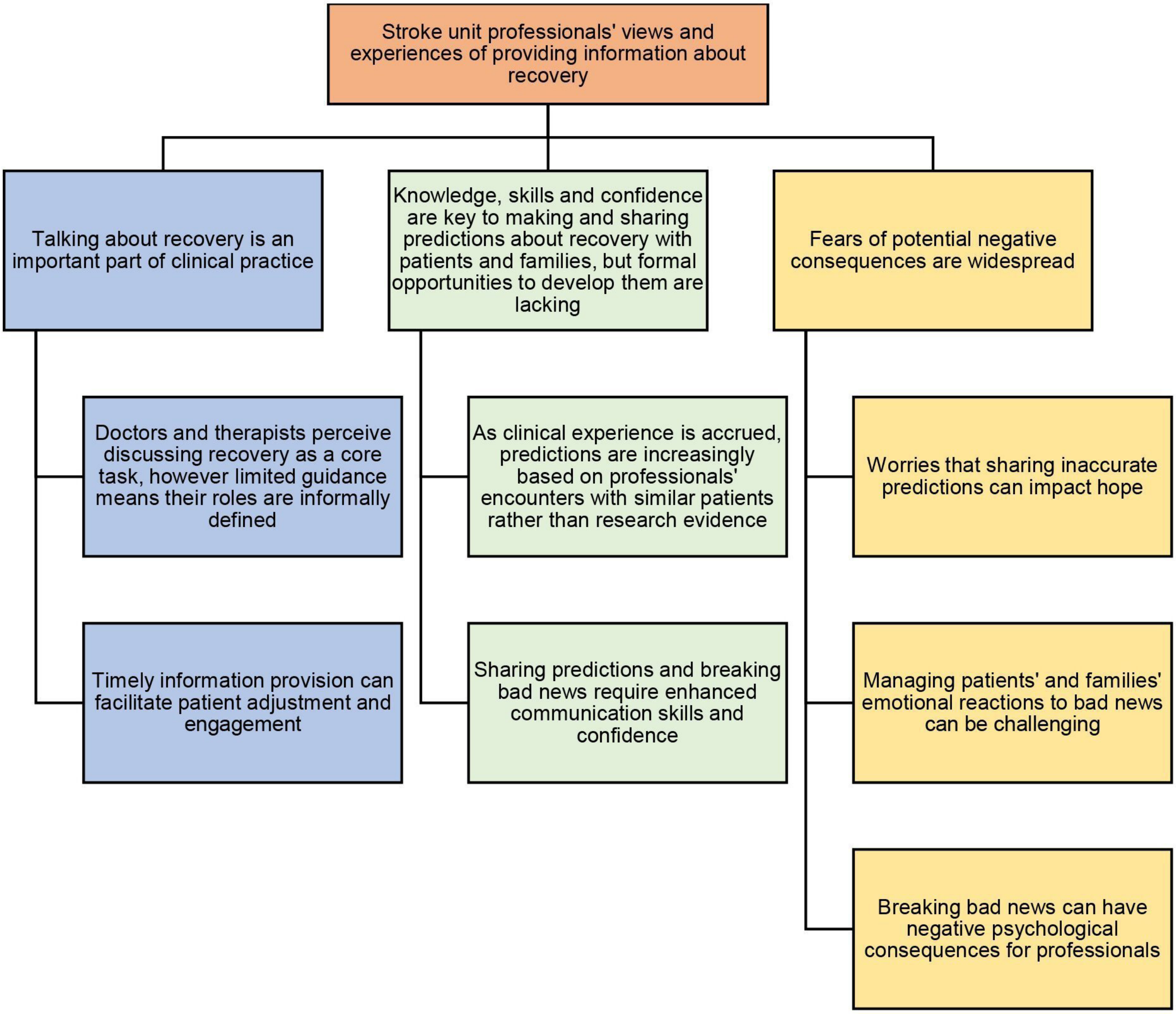

Figure 1 Identified themes.

Mean interview length was 46.13 (SD=12.96) minutes (range=28.5–78.43 min).

Three themes and seven subthemes were generated (see figure 1). Views and experiences were similar across sites; however, some divergence in subthemes was identified across sites and will be discussed where it occurred.

Theme 1: talking about recovery is an important part of clinical practice

Subtheme: doctors and therapists perceive discussing recovery as a core task; however, limited guidance means their roles are informally defined

Doctors and therapists perceived that formulating recovery predictions for individual patients was a common clinical task; it underpinned their treatment planning and decision-making, both individually and as a team, for example, at MDT meetings. Sharing these predictions (alongside more general information about the process of poststroke recovery) with patients and families was an important part of their role as an MDT member, and they prioritised this task even where their time was limited, for example, due to low staffing levels. Despite an absence of formal guidance, for example, locally or from relevant professional bodies, there was an informal understanding that they should provide information within their field of expertise, for example, medical information should be delivered by a doctor, both individually and within team settings, for example, in family meetings.

> It's so important to work as an MDT but I think […] delivering news about recovery […] needs to be from the person who's like the therapist in that area, so whether that's the mobility with the physios, the cognition and our language and swallowing. Experienced SLT, Site 1

Providing tailored recovery predictions was seen as the role of qualified professionals, while unqualified staff, for example, healthcare assistants, could provide general information or comment on progress in relation to improving function.

> I wouldn't mind the healthcare saying, "Oh, you've stood for that re-turn really well", you know, that's still an indicator of your recovery, isn't it. Like, "Oh, you were on a hoist last week when I came in, and now you're re-turning", […] It's like to the level of the profession, really. Experienced OT, Site 2

However, the absence of guidance at times could lead to confusion, particularly about nurses' roles. While some therapists felt nurses had busy workloads and more important priorities, others felt they were well-placed to discuss recovery, due to the round-the-clock nature of their work, which created opportunities to develop close relationships with patients and families. A nurse, however, described that while nurses provided support and reassurance, they would defer to multidisciplinary colleagues when asked about likely recovery, even when questions related to aspects of nursing care, for example, continence.

> I'll either arrange like a meeting with the doctors or the therapists. The therapists are fantastic, they will know the progress more than I will, you know, and be able to give them more of an update, but we try and keep the patient positive. Junior nurse, Site 2

The absence of established roles in providing information about potential recovery meant that some participants worried that overoptimistic messages about recovery could be conveyed by their colleagues. They believed that a lack of specific knowledge and limited MDT communication could affect the consistency of information, potentially resulting in confusion for patients and families.

> […] I think they feel sometimes like they have to give information, even if it's not the right sort of information. […] There's nothing worse than patients or relatives getting multiple information which is different from different specialties. Senior doctor, Site 1

Additionally, patients' and carers' preferences for information delivery could impact professionals' roles. For example, some therapists reported frustration that some patients and carers appeared more accepting of predictions provided by consultant doctors (specialists in diagnosing and treating stroke), perceiving them to have greater authority.

> They will take it better from the consultant because I think they recognise them as a figure of authority, so I think they respect their opinion more. Junior PT, Site 2

This was less concerning for others, who believed patients understood therapists' expertise in rehabilitation, and that discussions were facilitated by the trusting relationships they developed.

> We get to know a lot of the family and the patient, we spend a lot of time with them, so I think actually they do respect our opinion a little bit more, because I think we get to know them a bit more, like a personal level. Experienced PT, Site 1

Subtheme: timely information provision can facilitate patient adjustment and engagement

Providing information about the potential for recovery was deemed important due to perceptions of benefits to patients and families. While participants described how some patients could make functional improvements, they anticipated that most (particularly those undergoing in-patient rehabilitation) would endure at least some residual disability. They understood that the sudden and life-changing nature of stroke, potentially involving an overnight transition from independence to dependence, could be shocking and difficult for patients and families to process psychologically. This could lead patients and families to grieve, both for the functions patients had lost and the subsequent impact on their participation in previously enjoyed activities and roles. As a result, therapists described how discussing the long-term nature of the recovery process and role of rehabilitation, alongside personalised predictions of likely outcomes, could promote acceptance and adjustment, both for patients and relatives.

> The problem with stroke is that it's people can be fully independent and mobile and a stroke just happens like that […] that's obviously going to take time for them to come to terms with that and then like I say, if all they're doing is hanging on to the hope of well I can get through this because I know I'm going to walk again but they're not, somebody needs to say that to them. Experienced PT, Site 2

Some participants described how helping patients and families to understand the recovery process and the likelihood of regaining specific functions could help them to feel informed, reduce their anxiety and increase their sense of control over their uncertain situation. A minority saw benefits of providing specific predictions in supporting engagement with decision-making, for example, to inform plans for meeting postdischarge care needs and potential environmental adaptations. This was viewed as particularly important for relatives, whose roles in care provision could dramatically change.

> It can help them again like manage expectations of what they might be at the other end of it […] and what support the family might be needing […] to think about, and things like discharge destination, they might not end up going home to the family, that's a big thing to come to terms with. Experienced PT, Site 1

One participant described how information about likely outcomes could also inform decisions about rehabilitation aims and participation.

> If you give them the information […] in some patients it makes them realise, “Well, actually, I’m going to make some decisions about my rehab and what I want it to look like.” […] I think there’s some times where it helps because it puts things into perspective for them, helps them plan and guide us to guide their rehab. Experienced SLT, Site 2

Theme 2: knowledge, skills and confidence are key to making and sharing predictions about recovery with patients and families, but formal opportunities to develop them are lacking

Subtheme: as clinical experience is accrued, recovery predictions are increasingly based on professionals’ encounters with similar patients rather than research evidence

Prior to sharing tailored information with patients and families, participants described how it was necessary to formulate predictions about the likely extent and timing of recovery. They described how making such predictions could be challenging, although most considered similar factors, including lesion location and size, pattern and severity of initial deficits and response to therapy, alongside demographic factors and premorbid function.

> There’s expected recovery like I said, type of stroke, initial level of disability and […] then comorbidities and all that kind of stuff and age, can all help people to make a prediction of recovery but there’s always that case that goes against the grain. Experienced PT, Site 2

Participants described how their basic knowledge about the process of stroke recovery and factors that could influence it was evidence-based. However, junior staff described a greater reliance on research evidence to inform their predictions. Senior therapists discussed how their accrued clinical experience increasingly caused them to view the evidence base, and its application to individual patients, more critically. The uncertainty of the trajectory and wide range of factors impacting individual recovery could lead to anomalies, where patients’ recovery was not as they had anticipated. This underpinned a greater reliance on their clinical experience of the recovery patterns of similar patients, and thus led to increased confidence in their perceived predictive abilities over time.

> I find it very challenging really, because part as a physician, you know you rely on evidence, or you try to back up as much as possible on evidence to give accurate information, but you know, no two patients are the same and the variability is so significant that using research to guide people I find that very challenging. Senior doctor, Site 2

The influence of experience and its effect on confidence meant that junior therapists were perceived to provide varying amounts of, or different, information compared with their seniors. However, participants described how this impact was diminished through MDT working, through which junior therapists could access the knowledge and experience of senior colleagues, for example, through supervision.

> I’m quite keen on literature, but I think speaking to other colleagues, especially senior members of staff that have been here a long time, they’ll have seen these patients come through and they know what kind of progression they’re going to have. Junior OT, Site 2

Reliance on clinical experience was, however, problematic when it came to predicting long-term outcomes. Most participants rarely saw their patients after hospital discharge, so were unable to observe how their deficits, and progress observed in the acute setting, translated into long-term outcomes. Some described that patients’ performance might change in their home environment, but whether this improved with familiarity or deteriorated due to an absence of routine could be difficult to predict. While a minority of participants described how treating patients across the stroke pathway had been beneficial, most worked on the assumption that most recovery would occur during in-patient rehabilitation, with subsequent improvements more gradual, although some reported anecdotal evidence that gains could be made long after the initial stroke.

> Some of our therapists on the unit, they don’t see what [patients] do outside of here. And there’s some patients who you think will do really well and do really terribly once they’re home. Or vice versa, some people just need their environment back. So I think that experience [in the community] was invaluable, I don’t think you can get an insight into what’s next until you’re out there and you’ve seen it. And I think that helped me predict better the people in here. Experienced SLT, Site 2

Subtheme: sharing predictions and breaking bad news require enhanced communication skills and confidence

Therapists discussed how they were expected to provide predictions about recovery, including breaking bad news, to patients and families, even as a junior team member. This could cause anxiety, and professionals described lacking confidence.

> I think maybe sometimes the more junior staff are […] not worried about giving the news themselves, their concern is more around that they do it in a way that’s […] done properly […] they're more frightened that they going to make the situation worse if they do it badly, that’s what they're generally anxious, it’s not so much the news, it’s more around how they deliver it. Senior OT, Site 2

Such potentially challenging conversations required enhanced communication skills to impart information sensitively and empathetically, particularly where they involved breaking bad news, for example, if limited ongoing recovery was anticipated. However, little specific training was provided, and therapists described how the generic communication skills training in their professional qualifications did little to prepare them for real-world practice and the questions they faced from patients and families. Instead, they described learning as experiential, discussing how their skills and confidence were developed through observing their peers and trial-and-error learning.

> I've never had any formal training on how to break bad news […] I suppose I've just kind of learnt it over the years through probably getting it wrong a hundred times […] you should always be reflecting anyway on how you've done stuff and […] there are times when you think "Oh, Jesus, I shouldn't have done it like that, that was terrible". And then sometimes you kind of think, "Yeah, you know what, that went really well". Senior OT, Site 2

Although this process was supported by preparatory discussions with their colleagues and subsequent reflection (either individual or collective), this method meant those new to stroke could find early experiences challenging.

> We don't get any training actually. Again, I just think it comes from experience which, on the job, which I suppose when you're coming into it and you're new it's quite difficult. But watch, again watching seniors and things like that, seeing how they kind of do it. Junior PT, Site 1

Despite not viewing the provision of recovery information as part of the nursing role, a nurse described how professional training would not have provided adequate preparation in breaking bad news in prognosis. Doctors did not describe similar challenges.

> As a student […] to get signed off on the competencies we had to break some bad news, but it could've been like a lower level of like "I'm sorry Mr Smith you can't go home today, you're going to have to go home tomorrow because your medication's not ready" but not really breaking bad news about, not like the doctors have to do. Junior Nurse, Site 2

As a result of the experiential route to skill development, participants described variation in individual abilities.

> You're just expected to almost pick stuff up along the way, so I think as kind of giving information and advice to patients it's almost on your own clinical judgement, so my clinical judgement's probably going to be different from a [junior therapist] than it is to a [senior therapist], so we're probably going to clinically think a little bit differently. Experienced PT, Site 1

While some assumed that greater experience meant enhanced skills, not all agreed. In addition, learning from senior colleagues required that those acting as 'models' had themselves developed effective skills, which led some participants to worry about repetition of past mistakes.

> I think there is an unmet gap in education for people who step into the stroke service, you know you're learning on the fly […] but learning on the fly it has its own problems, because you know, you may end up doing the same thing people have done before, which hasn't worked. Senior doctor, Site 2

As a result, most participants felt that formal stroke-specific training involving strategies to share recovery predictions, manage expectations and break bad news would be beneficial. Although senior therapists reported that some breaking bad news training was offered by their organisations, this was perceived as being primarily aimed at senior, medical and/or palliative care professionals and none had therefore accessed it.

> I do think there has been a course on delivering bad news but I don't know, I suppose I'd look at that and think, well is that more for doctors delivering bad news type thing […] rather than us talking about our therapy goals that the patient's not achieving type thing, so I think it would be useful to have a course. Experienced SLT, Site 1

Theme 3: fears of potential negative consequences are widespread

Subtheme: worries that sharing uncertain predictions can impact hope

As a result of the uncertainty of the poststroke trajectory, many participants described anxiety about sharing individualised predictions with patients and families, due to potential inaccuracies. They worried about receiving complaints should the patient improve less than predicted and described a potential for loss of trust in the therapeutic relationship following imprecise predictions, even where greater than anticipated recovery was achieved. As a result, many were reticent to share specific predictions, at least until they were very confident in their accuracy, and stressed the importance of conveying uncertainty.

> What you don't want is somebody to come back and say, "He's walking now and you said he never would." But equally they say, "They're not walking now and you said he would." And that's what you want to avoid. Senior doctor, Site 1
>
> It's difficult to predict and then if I say the wrong answer and say […] "oh yes, it's definitely going to improve," however, if that's not the case and the patient comes back […] and says 'actually, staff nurse, said, you know, continence was going to improve for my partner but now it's just the same, why have you lied to me?' you know, it's a tricky one. So it's erring on the side of caution. Junior Nurse, Site 2

Further, participants discussed the fine line between giving and taking away hope; they understood their powerful position as 'expert' and took care when sharing predictions. While they felt it necessary to prepare patients for possible ongoing disability, they worried that receiving such information could result in them losing hope, which could affect their participation in therapy and further limit their recovery.

> For some people [receiving information] could have a real negative effect and they feel like giving up and they don't engage in therapy and they've still got potential to improve. Experienced PT, Site 2

They attempted to support hope through presenting 'bad news' about affected functions alongside 'good news' about those preserved and encouraged a focus on what was amenable to change through therapy, for example, through goal setting. However, they were equally anxious that patients did not maintain unrealistically high hopes for recovery, which, if unfulfilled, could negatively affect their mood. These concerns led to a degree of paternalism, with several participants suggesting a tendency to withhold positive predictions to prevent later disappointment should they fail to transpire.

> You don't really want to get their hopes up and then for them to not get where you expected, so I hold back certain information on what I think with families, I think it's appropriate. Experienced PT, Site 1

Subtheme: managing patients' and families' emotional reactions to bad news can be challenging

Therapists worried about how they would manage patients' and families' emotional responses to information about an unfavourable outlook, which could include sadness and anger. Some expressed particular concern for patients already experiencing mood difficulties, describing how such symptoms were not uncommon after stroke and could be exacerbated by rumination on the potential for long-term disability, causing decreased engagement in rehabilitation. Participants described potential strategies to limit distress, which included early management of patients' and families' expectations and 'drip-feeding' information over time to reduce sudden shock, and providing information in a team setting, to highlight progress in some therapies, even where it was not expected in others. Some described a temptation to present overoptimistic information to provide encouragement and hope (which they mostly resisted), although in the presence of psychological difficulties, others suggested they might avoid or delay discussing negative predictions until the patient's mood had improved.

> Definitely when I first started, I avoided it like the plague. Experienced SLT, Site 2

These hints of paternalism suggested therapists were trying to manage their patients' emotional responses in their best interests, and they appeared unaware of the potential impact of withholding such information. Most, however, perceived that instilling realistic expectations was important and discussed employing careful wording to help patients and families focus on the more positive aspects of the information they were conveying.

> I would say it's looking like you might not get back up on your feet and be walking independently. But everything we're doing is about trying to improve your quality of life as best you can. […] And when you think about sort of speech, swallow, transfers, continence, mobility, cognition, you can usually say there's four or five things that are improving a little bit. And you can sort of distract them a little bit from the fact that they may not actually be walking again in due course. Senior doctor, Site 1
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> You have to be really realistic with patients' families and you can't just pretend it's all going okay and then it gets to whatever mark and it's not. And […] the more realistic that you are, the easier it makes the conversations that are going to happen. Junior PT, Site 2

Therapists reported responding to patients' and families' distress by 'checking in' with them following bad news delivery and listening to their concerns. Where a patient's angry response impacted the therapeutic relationship, therapists described seeking a change of therapist or approaching further conversations about potential recovery alongside a senior colleague. Referrals for psychological support could be made at site 2, which could provide opportunities for patients to process their feelings and support adjustment; no such provision was available at Site 1.

> Sometimes we might take them out the room, or sometimes after the family meeting I might go back […] and just say, "how are you feeling?", and, "we're really sorry we had to tell you that". Experienced OT, Site 2

Subtheme: breaking bad news can have negative psychological consequences for professionals

Most therapists described how sharing information about an unfavourable outlook could cause them to experience anxiety, stress and sadness. They worried about their own abilities to impart information sensitively and to manage patients' and families' reactions, particularly those whose expectations for recovery had not been met and where they perceived the MDT was at fault. Professionals described how accruing experience increased their emotional resilience and ability to cope. However, they empathised with patients' grief and described greater emotional investment when they had spent more time in close therapeutic relationships.

> It's really draining. You do go home and wonder if you're doing a good job. I had a bit of a nightmare family where the son sat next to me in the family

> meeting and just kept telling me that I was giving up on his mother. […] and I can't get upset because I can see why because they're angry, because they're angry that this horrible thing has happened. Junior PT, Site 2

> Sometimes you almost have to take yourself out of the situation almost, and it's difficult because you almost have an attachment with that patient, because they're yours, you spend a lot of time with them, but almost put yourself in kind of their shoes a little bit and kind of take the flack. Experienced PT, Site 1

Despite these challenges, participants reported a lack of formal support, for example, counselling, to manage their emotions, with some describing that, although it could be beneficial, they would be unlikely to proactively seek it. Instead, therapists described how positive and trusting team relationships enabled them to access informal personal support. They engaged in debriefing, and personal and collective reflection following information delivery, which could be reassuring and help them to process their emotions.

> A lot of time even just after the family have left the room after a meeting all sitting together and going "well that was awful" or "you know what, that was good" or "I think they might have taken that" or "you know what, I don't think they took that, let's think about this going forward", that can also help as well. Junior PT, Site 2

> I feel lucky that I work in a big team and there's always a [senior] around. If I am feeling that it's getting to me, psychologically, I'd just go and speak to one of them, I think. But, yeah, sometimes you get a bit of a tear in your eye, well, quite often. You've got to try and hide it. Experienced OT, Site 2

Discussion of the emotional cost to breaking bad news was largely limited to therapists; doctors did not describe similar challenges.

DISCUSSION

The results of this study highlight a range of challenges experienced by professionals involved in providing information about poststroke recovery in two stroke units in England. Although these professionals typically identified benefits in providing information and felt this was an important part of their role, their skills were developed through experience with little access to formal training and guidance. This could result in perceived variability in information delivery and decreased confidence in this area of practice, particularly when breaking bad news, alongside a range of psychological effects, including worry and sadness, which could accompany such conversations. Underlying these concerns were the uncertain trajectory of stroke recovery and concerns for the emotions and engagement of patients, whom professionals feared could be negatively affected by the receipt of information that might not match their expectations for recovery and/or may not transpire.

Some limitations must be acknowledged. Although purposive sampling permitted in-depth exploration of the views of a range of healthcare professionals with various experience levels, we excluded non-qualified staff and nurses were under-represented, which prohibited detailed exploration of their views. Additionally, participants were recruited from two in-patient stroke units in one English county, and their experiences may be context specific. Conversations about recovery are likely to continue along the stroke pathway, and future research is needed to explore the experiences of community-based professionals.

Few previous studies have considered the roles of MDT members in providing information about poststroke recovery, and our results highlight a lack of clarity about who should provide information. In an investigation exploring how neurorehabilitation teams discuss rehabilitation potential, Peel *et al* identified a similar lack of consensus.[4] Our wider ethnographic study revealed this could contribute to the provision of conflicting information to patients and families, which could cause confusion.[7] This potential could be ameliorated by a collaborative team approach to information provision, including sharing of recovery predictions and whether they had been provided to the patient and family, across the team.[7] This is particularly important where information provision requires breaking bad news, which is now more frequently seen as an ongoing dialogue involving conversations with multiple professionals over time, rather than the longstanding notion of a one-off consultation between doctor and patient.[2 29] Like others, our research highlights how most stroke professionals view discussing recovery as a key part of their role.[4] However, there remains a lack of clarity in the roles of nursing staff, which requires further investigation. While they appear potentially well-placed to respond to patients' and families' questions due to regular contact[15 30] and have an acknowledged role in supporting adjustment,[31] they may feel uncomfortable discussing recovery outlook and defer to other professionals.[6 23 32] Having agreed and understood roles for multidisciplinary professionals is likely to be an important step towards ensuring that patients' and carers' information needs are consistently met. Flexibility in the implementation of these roles should, however, be employed in line with patients' wishes: As was perceived by some professionals in our study, Cheng *et al* identified patients' preferences to receive prognostic information from a doctor.[33]

Our study highlights how communication skills to undertake conversations about recovery are learnt through experience, resulting in variable abilities and confidence levels of MDT members, rather than through formal training, resonating with recent research in stroke and other neurological conditions.[2 14 24] Guidance cementing the roles of different professionals in this complex task may support access to appropriate and specific training, for which there is a clear need. Such training may incorporate existing models of breaking bad news, which can enhance the confidence and performance of professionals.[34] One such model, known as COMFORT (Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative Messages, Team)[29] has been suggested for use in neurorehabilitation,[35] due to its incorporation of guidance around family engagement and consideration of the team context in which information is provided.[2 29] Phillips *et al* identified how training in breaking bad news based on this model could improve the confidence of stroke professionals.[16] However, their study took place within a single community-based stroke team, with the intervention tailored to their needs. Further research is required to identify and evaluate interventions, including best practice guidance for professionals working in this area, which can be implemented across stroke services. Based on our wider ethnographic study, a structured intervention to improve professionals' confidence and skills in providing information about recovery is currently in development[36]; future work is required to evaluate whether such an intervention is feasible to deliver in clinical practice and whether its implementation has the intended effects on patients' satisfaction, adjustment and involvement in decision-making.

Skills to formulate prognoses are required prior to the provision of information about poststroke recovery, yet despite their demonstrated involvement, our results echo previous research in suggesting a lack of available training for professionals other than doctors.[24] A range of evidence-based tools is available to support predictions,[37] and a 2023 update to UK stroke guidelines cautiously advocates their use.[21] There is some evidence that using such tools can increase staff confidence in the predictions shared with patients and families, however, there can be associated costs for equipment and staff training.[20] As a result, implementation into clinical practice has been slow,[37] impeded by limited access to professional training, in both the interpretation and subsequent communication of findings to patients and families. The results of this study suggest that prognostic tools and associated training may particularly benefit junior professionals who lack the clinical experience relied on by senior professionals to predict the likely timing and extent of recovery, as well as potentially increasing the confidence of all.

Professional-focused interventions to enhance prognostic discussions and breaking bad news should address the emotional toll of discussing prognosis and breaking bad news on professionals highlighted in this study and substantial previous research,[4 14 38] which may lead to occupational stress and burnout.[38 39] Providing information about recovery is particularly challenging in stroke and other neurological conditions, where there is potential for uncertainty in recovery predictions. Like our study, previous research has described professionals' discomfort with this uncertainty and their subsequent worries that sharing inaccuracies can result in negative consequences, including prolonging false hope, disappointment and a loss of trust in the therapeutic relationship.[14] Therapists in particular require such trust, risking reduced patient engagement and effort in rehabilitation should patients fail to accept the potential benefits of the treatment they offer.[40] In Bright *et al*'s study, professionals managed this through an avoidance of discussing the future with in-patient stroke survivors, which the authors suggest could increase patients' distress.[23] They, and other researchers, have discussed how sharing and acknowledging such uncertainty can be important for patients and families, and for some, can promote hope.[7 24 41] Improved access to training (as described above) could enhance professionals' confidence in providing information and support them to openly convey uncertainty. Our study has identified the importance of informal MDT support and relationships between professionals, alongside more formal processes such as clinical supervision and debriefing, which have been previously identified as helpful for managing emotions in other studies.[4 42]

Finally, our study highlights the potential ethical issues in discussing prognosis with patients and their families, emphasising the power held by professionals as keepers of information (for further reading, see references 43–45). Despite the perceived advantages of providing information about recovery, some professionals in this study described delaying or avoiding providing information about recovery outlook when they perceived it might negatively affect patients' motivation or result in distress. Such behaviour is perhaps understandable, given the potential impact on patients' motivation should they believe their goals to be unachievable, and the perceived effect that such disengagement could have on their outcomes. These findings echo those from previous studies in stroke[16 17] and neurological rehabilitation more generally,[4 14 41] including one conducted more than 20 years ago, suggesting little change has occurred in this time.[17] To our knowledge, however, professionals' fears have not been formally explored within the literature; anecdotal evidence suggests that some patients may find negative predictions motivating. Research into patients' perspectives emphasises that most would prefer to receive information; however, they would prefer to do so in ways which help them to maintain hope for their recovery and future.[33] The effects of sharing information are, however, likely to be individual, and thus decisions around whether or not (and when) to provide prognostic information should be made in collaboration with the patient.[19 24] Training for professionals should promote strategies to communicate information in ways which can empower patients and help them to maintain hope, while preparing them for the road ahead[15 19]; balancing the right to know with minimising distress.[46] Psychological support for adjustment is likely to be required where information is unfavourable.

In conclusion, stroke unit professionals perceive that providing information about recovery, including individualised predictions, has important benefits to patients and carers. However, they lack clarity over their roles and confidence in how to deliver such information without causing confusion, distress and disengagement from rehabilitation. Given the importance of such information, professionals require additional guidance, support and training to confidently engage in this important area of clinical practice. Further research should identify how such training could best be delivered and implemented into clinical practice.

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