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What influences provision of information about recovery on stroke units? A focused ethnographic case study

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ABSTRACT

Objective: Patients and carers frequently report dissatisfaction with post-stroke information provision. This study aimed to develop an in-depth understanding of the factors influencing provision of information about recovery in stroke units.

Methods: Focused ethnographic case-studies in two UK stroke units, including non-participant observations and semi-structured interviews with professionals, patients and carers, and documentary analysis. A Framework approach to analysis was undertaken.

Results: Twenty patients, 17 carers and 47 professionals participated. The unpredictable recovery trajectory led professionals to present prognostic estimates as uncertain possibilities. The need to maintain patients' motivation limited sharing of negative predictions, and generic information over-emphasised the importance of therapy in recovery. A structured multidisciplinary team approach to delivering information improved consistency. Complex clinical reasoning was required to identify and meet patients' needs. Hospital environments and routines restricted opportunities for dialogue, particularly with carers.

Conclusions: The process of providing information about post-stroke recovery is complex, requiring enhanced clinical reasoning and communication. The challenges faced by professionals are numerous and if not addressed can result in suboptimal provision.

Practice implications: Professionals should develop a co-ordinated multidisciplinary approach to information provision; and engage in dialogue to ensure a tailored approach to identifying and meeting patients' and carers' information needs.

1. Introduction

Stroke is a leading cause of disability worldwide [1] and can result in a range of physical and psychological difficulties [2,3]. Rehabilitation typically begins in hospital-based stroke units, delivered by multidisciplinary teams (MDTs), and some functional recovery is nearly always possible. However, the road to recovery can be long; ~a third of patients leave hospital with continuing disability [4], and ~one tenth are discharged to institutional care [5].

Post-stroke information provision has frequently been reported as inadequate [6]. Evidence suggests particular dissatisfaction with information about recovery [7,8], which in stroke can relate to both medical recovery, as well as physical, functional and psychological improvements. In this study, we use the term 'information provision' in relation to recovery to mean communication between professionals and patients/ carers, that includes at least one topic from: progress to date, general information about the process through which recovery occurs, and tailored prognostic information about the likely timing and extent of recovery. This information is usually provided in a process of two-way communication, primarily formal and informal conversations, with both professionals and patients and/ or carers as active participants.

Evidence suggests that active post-stroke information provision has the potential to improve patients' mood symptoms and quality of life [9]. In relation to recovery, research in stroke and other neurological conditions (primarily from studies conducted in Western countries [10]) suggests that providing such information can promote patients' adjustment to continuing disability [11,12] and support shared decision-making and planning [13,14]. Professionals however face challenges in providing this information, resulting from the uncertain recovery trajectory and the need to maintain patients' engagement in

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rehabilitation, particularly when confronting a negative outlook [15–18]. Additionally, information provision involves a range of multidisciplinary professionals, including nurses and therapists, who report a lack of training, particularly in breaking bad news, and find these experiences stressful [11,18,19].

Recently published UK stroke guidelines advocate that professionals share prognostic information to manage patients' and carers' expectations of goal achievement and outcomes and underpin collaborative discussion about appropriate treatment pathways [20]. Little is however known about how this works in practice, and few studies have simultaneously examined both provision and receipt of information about recovery; most rely solely on the reports of either providers, i.e., professionals (often from a single discipline, e.g., Speech & Language Therapists (SLTs) [21]), or recipients, i.e., patients [22,23] or carers [24]. Only one study has contemporaneously explored the views of patients and professionals and observed practice [16,25]; this study primarily focused on out-patient physiotherapy and was conducted over two decades ago.

As part of a wider project to improve provision of information about recovery, the present study aimed to address this evidence gap by developing an in-depth understanding of the factors influencing the provision of information about recovery in stroke units. The scope of our study was broad, aiming to explore what influenced whether, when, and how information (both verbal and written) was provided by stroke unit professionals and received by patients and their families. We considered 'recovery' as a broad concept, encompassing medical, physical/ functional, and psychological improvement, and were interested in information provided about progress to date, recovery processes, and prognostic predictions.

2. Methods

Methods are reported in accordance with the Standards for Reporting Qualitative Research (completed checklist available from https://osf.io/qfpwc). A focused ethnographic case-study approach was employed, comprising non-participant observations conducted sequentially at two sites (three-four days per week for a continuous period of three-four months at each site), subsequent semi-structured interviews with participants, and documentary analysis. Combination of organisational ethnography (such as focused ethnography) and the case study approach permits researchers to develop in-depth holistic understanding of phenomena (in this case, provision of recovery information) in its natural context within and between sites [26]. Observations progressed from general observations of unit practice (conducted in open ward areas and arenas for professional communication) to specific observations of recruited patients/ carers' interactions with professionals (including during therapy sessions and formal meetings). Face-to-face semi-structured interviews with patients and carers were undertaken ~six weeks post-discharge; professionals were interviewed following completion of observations at each site. Documents collected included professionals' records of information provided (extracted using a standardised form from patients' records), unit policies, and written information provided to patients.

The study setting was the stroke unit, which was chosen as a mandatory component of UK stroke care, where > 70% of patients spend at least 90% of their hospital stay [27]. UK guidance states that units should be staffed by a specialist multidisciplinary team, who meet at least weekly to exchange information about their patients [20]. Although UK guidelines recommend the sharing of information with patients and families, they do not dictate how this should be achieved, and information is typically provided verbally (through informal day-to-day communication or in formal meetings) or in writing (e.g., leaflets). Two in-patient stroke units were selected due to their divergent approaches to provision of recovery information.

At each site, ten patients were purposively and heterogeneously sampled, to ensure a range of ages and pre- and post-stroke functional abilities. Eligibility criteria for all participants were: aged ≥ 16 years and English-speaking. Additionally, patients were required to have a primary diagnosis of new stroke and be receiving rehabilitation. Carers were relatives or friends of participating patients. All qualified professionals at each site were invited to participate in observations; a purposive sample was subsequently approached for interviews, to reflect a range of professions and experience levels. Patients were identified and approached for recruitment during their hospital stay. All participants provided written informed consent prior to participation; where stroke survivors lacked the capacity to provide consent, a consultee declaration was sought. Specific information sheets and consent forms were developed to support those with communication difficulties; information sheets and consent forms are available at: https://osf.io/2n3vd/files/osfstorage/65fcae4b637c700172e41486. Patients with aphasia were supported to participate in interviews; those deemed to lack capacity to participate in an interview were not included. Participants were assured they could withdraw consent at any time; explicit verbal consent was obtained prior to the start of each observation/ interview.

This study was undertaken as part of the lead author's PhD research (LB); she completed data collection under the supervision of the other authors. Prior to her PhD, LB gained significant qualitative research experience on a range of stroke studies. She was unknown to participants prior to the study. During the study, she maintained a reflexive diary, in which she recorded her thoughts, assumptions, decision-making and early hypotheses. Emerging findings and alternative interpretations were discussed at regular meetings with the research team.

Demographic data were collected from participants at the time of recruitment. Fieldnotes were recorded based on a qualitative framework informed by guidance from Spradley [28], who distinguishes between three types of account: a condensed account made during the observation; an expanded account, in which condensed notes are developed based on the initial notes and researcher's memory; and a fieldwork (reflexive) diary, in which the researcher explores their own experiences and ideas. Interviews were conducted using flexible topic guides [29] developed specifically for the study, based on our research questions and the findings of a previous systematic review (see https://osf.io/2n3vd/files/osfstorage/65fc9fc999b3460180aa2d32). Interviews took place in participants' homes (patients/ carers) or workplace (professionals) and were audio-recorded and transcribed verbatim.

All data were managed in NVivo [30]. A Framework approach to analysis was undertaken, following a five-stage process of familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation [29]. For general observation and professional interview data, a previously developed thematic framework was employed and adapted. This framework was initially developed through inductive line-by-line coding of the results of articles included in a systematic review exploring the experiences and views of those involved in providing and receiving information about recovery in acquired neurological conditions [10]. The framework was further developed using an iterative process during the familiarisation stage (a combined deductive and inductive approach). A new framework was inductively developed for patient-specific data (focused observations, interviews, documentary records); these data were managed separately. Codebooks are available at https://osf.io/2n3vd/files/osfstorage/6601e3b9b3a1e3000e7df10f. Data in both datasets were coded according to the framework (indexing) and displayed within matrices (charting), with summaries of data relating to each participant/ observation for each code developed, staying as close to the original text as possible. The views and experiences of participants in each group were compared and contrasted in an interpretation stage, developing overall summaries for each code and examining them for areas of commonality and difference.

As a final stage in the analytic process, to facilitate triangulation between sources, a third NVivo file was created, in which the coded data from the two datasets were compared and contrasted. This involved a process of looking across the codes generated from each dataset and grouping them together according to the research question they addressed. All data relating to each research question were then reviewed to identify areas of similarity and difference, thus facilitating comparison between the views and experiences of professionals, patients, and carers. Throughout the analytical process, analytical memos were developed to capture emerging insights, concepts, or issues. Emerging themes were reviewed independently and subject to in-depth discussion across the research team to reach consensus.

3. Results

3.1. Setting and sample characteristics

Site 1 was a 35-bed stroke and neurology ward, providing services for hyperacute, acute and rehabilitation patients, with an average length of stay of ~six weeks. Site 2 was a 12-bed stroke rehabilitation ward, housed within a wider unit comprising a hyperacute/ acute ward and two further rehabilitation wards; average length of stay was ~three months.

Overall, 20 patients, 17 carers and 47 professionals participated in observations over 83 h. Most staff participants who were subsequently approached for interview agreed (N = 19), although no nurses agreed at Site 1. Ten patients and four carers participated in interviews; one patient participant at Site 1 declined and three lacked capacity to consent (in each case, their carer took part). Due to the COVID-19 pandemic, only three patients from Site 2 were interviewed. Documentary analysis from the clinical records of these patients, and informal conversations during observations did however contribute to the analysis. Documentary data were collected from the electronic medical records of all patient participants.

Patients', carers', and professionals' demographic details are presented in Tables 1–3.

3.2. Themes

Four main themes comprising eight subthemes were generated (Fig. 1). Illustrative numbered quotes *(Q)* are presented in Table 4 and indicated in parentheses following the statements they support. Data sources of statements (observations *(O)*, interviews *(I)*, documents *(D)*) are indicated within the text or in parentheses following each statement.

Table 1
Patients' demographic data (NIHSS: National Institutes for Health Stroke scale).

	Observations		**Interviews**	
	Site 1 (n=10)	*Site 2 (n=10)*	*Site 1 (n=7)*	*Site 2 (n=3)*
Female (%)	5 (50%)	4 (40%)	3 (43%)	2 (66.7%)
Ethnicity				
- White	9 (90%)	90 (90%)	6 (86%)	3 (100%)
- Asian or Asian British	1 (10%	1 (10%	1 (14%)	-
Mean (sd, range) age (years)	72.6 (13.86, 52-93)	65.1 (11.21, 47-85)	67.14 (12.14, 52-85)	68.67 (14.84, 56-85)
Language ability on admission				
- Normal	4 (40%)	1 (10%)	3 (43%)	1 (33%)
- Dysarthria	3 (30%)	4 (40%)	3 (43%)	1 (33%)
- Aphasia	3 (30%)	5 (50%)	1 (14%)	1 (33%)
Symptoms				
- Left hemiparesis	5 (50%)	4 (40%)	5 (71%)	2 (67%)
- Right hemiparesis	5 (50%)	6 (60%)	2 (29%)	1 (33%)
Mean admission NIHSS score (sd, range)	12 (9.12, 2-25) (n=9)	12.2 (9.85, 2-29)	9.67 (7.53, 2-21) (n=6)	8.33 (4.73, 3-12)
Mean length of stay in days (sd, range)	31.6 (27.98, 3-76)	52.1 (46.43, 6-144)	26.14 (24.96, 3-76)	22.33 (25.74, 6-52)
Discharge destination				
- Home	8 (80%)	7 (70%)	7 (100%)	3 (100%)
- Residential care	0 (0%)	3 (30%)	-	-
- Nursing care	2 (20%)	0 (0%)	-	-

Table 2
Carers' demographic data.

	Observations		**Interviews**
	Site 1 (n=7)	*Site 2 (n=10)*	*Site 1/ Overall (N=4)*
Female	4 (57%)	7 (70%)	3 (75%)
Ethnicity			
- White	7 (100%)	9 (90%)	4 (100%)
- Asian or Asian British	-	1 (10%)	-
Mean (sd, range) age (years)	50.17 (9.88, 34-62) (n=6)	57.57 (22.14, 30-90) (n=7)	50.25 (11.79, 34-62)
Carer relationship to patient			
- Spouse	1 (14%)	2 (20%)	1 (25%)
- Child	3 (43%)	4 (40%)	2 (50%)
- Sibling	1 (14%)	1 (10%)	-
- Grandchild	1 (14%)	-	1 (25%)
- Niece/ nephew	1 (14%)	-	-
- Parent	-	2 (20%)	-
- Friend	-	1 (10%)	-

Table 3
Professionals' demographic data.

	Observations		**Interviews**	
	Site 1 (n=19)	*Site 2 (n=28)*	*Site 1 (n=9)*	*Site 2 (n=10)*
Female (%)	16 (84%)	23 (82%)	8 (89%)	7 (70%)
Ethnicity		*(n=27)*		
- White	16 (84%)	23 (85%)	8 (89%)	9 (90%)
- Asian or Asian British	2 (11%)	4 (15%)	1 (11%)	1 (10%)
- Black, Black British, Caribbean, or African	1 (5%)	-	-	-
Mean (sd) age (years)	34.63 (9.89; n=16)	36.08 (12.37; n=26)	31.5 (8.05)	33 (9.09)
Professional background				
- PT	8 (42%)	5 (18%)	4 (44%)	2 (20%)
- OT	4 (21%)	4 (14%)	3 (33%)	3 (30%)
- SLT	1 (5%)	6 (21%)	1 (11%)	3 (30%)
- Therapy assistant	1 (5%)	3 (11%)	-	-
- Nurse (including Discharge Coordinators)	2 (11%)	4 (14%)	-	1 (10%)
- Physician	1 (5%)	2 (7%)	1 (11%)	1 (10%)
- Social worker	2 (11%)	3 (11%)	-	-
- Dietician	-	1 (4%)	-	-
Experience in stroke care				
- <1 year	9 (47%)	4 (14%)	3 (33%)	1 (10%)
- 1-5 years	5 (26%)	16 (57%)	3 (33%)	7 (70%)
- 6-10 years	-	1 (4%)	-	1 (10%)
- >10 years	5 (26%)	7 (25%)	3 (33%)	1 (10%)

3.2.1. Challenges in communicating recovery uncertainty can cause confusion and frustration for patients and families

3.2.1.1. Predictions as uncertain possibilities. Most professionals discussed how providing information about recovery included formulating and sharing predictions about the likely timing and extent of improvements. They described challenges in making individual predictions, which were impacted by a wide range of interacting factors, including medical factors, (e.g., lesion location and size), premorbid characteristics and comorbidities, the extent (severity and pattern) of deficits and

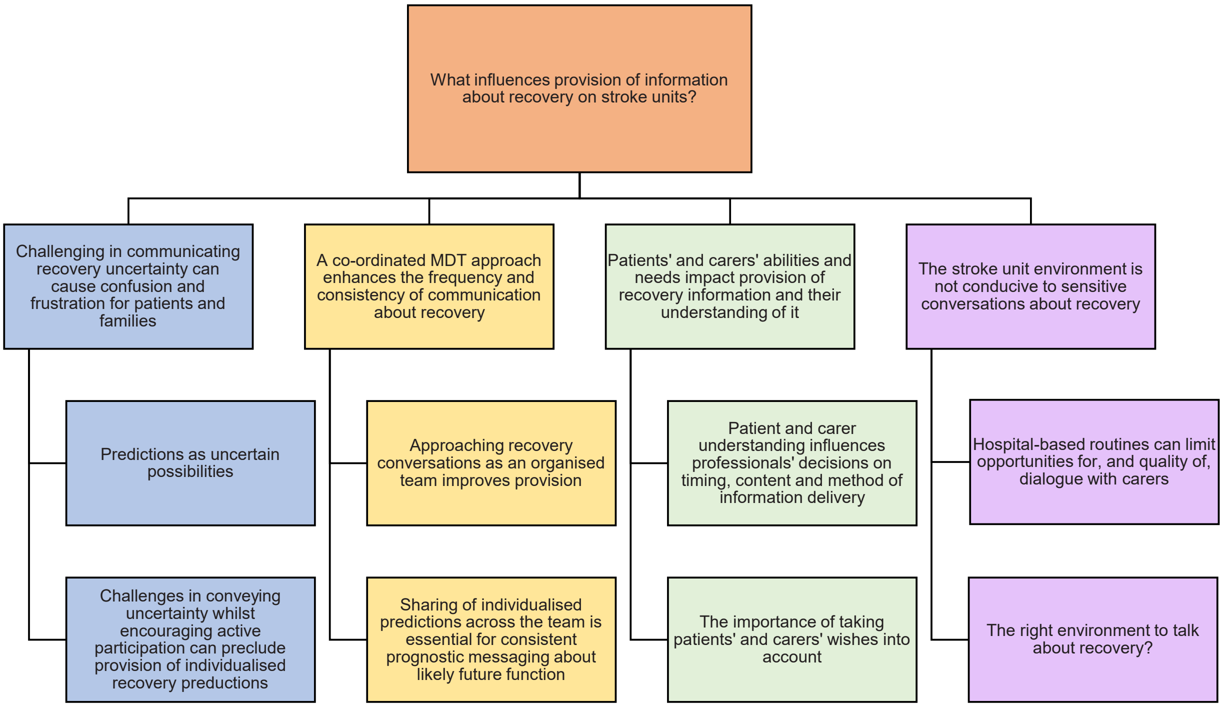

Fig. 1. Themes.

degree of spontaneous recovery *(Q1)*. Predictions were developed using clinical judgement, following assessment and history-taking. Professionals' skills were reportedly learned through experience with similar patients, rather than formal training, creating challenges for junior professionals *(Q2)*.

The uncertain trajectory also created challenges; even experienced professionals described how some patients with negative indicators improved more than first anticipated, and vice versa *(Q3)*. As a result, few were willing to share their early predictions with patients and families; their confidence in them however grew following observation of patients' spontaneous recovery and responses to therapy *(Q4)*. Despite this, professionals discussed the importance of highlighting the continuing uncertainty in their communication with patients and families, fearing predictions which later proved false could result in unnecessary loss of, or overly optimistic, hope for recovery *(Q5/6)*.

Few described receiving training in communicating uncertainty and observations revealed their attempts to convey it through direct statements and more subtle use of conditional language *(Q7)*, which patient interviews suggested could be missed by recipients. Some professionals felt presenting uncertainty, rather than a definite negative outcome, could provide hope for patients and families. Interviewed patients and carers described largely accepting this as the nature of the condition, believing their prognosis was unknowable *(Q8)*.

3.2.1.2. Challenges in conveying uncertainty whilst encouraging active participation can preclude provision of individual recovery predictions.

Observations of professionals' communication revealed their understanding that engagement in therapy was necessary to achieve functional recovery, with increased motivation believed to enhance it *(Q9)*. During therapy sessions, which require effortful participation, therapists' communication reinforced this message, praising effort and highlighting short-term progress. This indicated that recovery resulted from patients' efforts and signalled it would continue, thus motivating them to continue applying themselves; these sentiments were echoed by patients *(I) (Q10/11)*.

Aware that patients and carers could thus expect a full recovery, professionals simultaneously sought to manage their expectations by providing generic information, e.g., about the long-term and uncertain nature of post-stroke recovery *(O/I)*. Expectation management was deemed essential to prevent the maintenance of 'false hope', where beliefs that the patient would return to their pre-stroke state were upheld, even where they were experiencing significant disability; this featured prominently in professionals' interviews and observations of inter-professional communication *(Q12)*.

Where false hope was maintained and the expected recovery was not achieved, professionals worried that patients would experience disappointment and distress *(Q13)*. However, whilst generic information provision allowed professionals to communicate realistic hope, observations revealed it was often vague and lacked detail, e.g., about the exact timescales for recovery and mechanisms through which it occurred (*Q14*). Where individual predictions about outlook could be formulated, professionals worried about sharing them with patients, fearing that any negative information could impact patients' motivation, potentially causing disengagement with therapy and thus reducing the chances of achieving optimal outcomes *(Q15)*. Such predictions were therefore rarely observed during therapy sessions. However, in formal family meetings (where professionals invite patients and carers to discuss patients' difficulties, therapy, and progress), professionals sought to help patients realise that their desired recovery may not be achieved *(O/I)*. Discussion of the likelihood of recovering specific functions, and patients' anticipated recovery at specific time-points supported planning and decision-making, although predictions remained couched in uncertainty (*Q16*). Despite professionals' concerns, whether the outlook was perceived to be positive or negative, observations revealed little impact on patients' subsequent engagement. However, clear strategies were used to deliver this information, including promoting focus on short-term, achievable goals and highlighting functions amenable to change through rehabilitation, which promoted hope (*O/I*; *Q17/18*).

Where individual predictions were not provided (usually in the absence of family meetings, particularly at Site 1), the result of generic information provision meant patients and carers commonly believed predicting recovery to be impossible; their understanding thus focused on time, therapy provision, and effort *(Q19)*. During interviews, some

Table 4

Illustrative quotes (OT: Occupational Therapist; SLT: Speech & Language Therapist; PT: Physiotherapist).

Q1	*“I think everyone is so different and yeah, everyone just does so differently, even somebody who’s had exactly the same stroke, they might be the same age, their recovery will be so different, I think it depends on so many factors.”* Junior OT, Site 1
Q2	*“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.”* Junior PT, Site 1
Q3	*“We’ve got a chap on the ward at the minute and my hunch was oof, this man’s not going to very far, he’s fairly elderly, he’s got quite a lot of comorbidities, very drowsy, however he’s actually picked up and doing quite well.”* Senior Therapist, Site 1.
Q4	*“Maybe not straightaway, [.] because I think although you have that gut feeling you might be wrong and you see patients that you come back to the day after and the, the way they present is slightly different [.] I think usually after kind of two or three sessions you’re getting an idea then of where they’re at and maybe at that stage you’d start to be verbalising that.”* Junior PT, Site 1.
Q5	*“You always have to temper it with that uncertainty.”* Stroke consultant, Site 1
Q6	*“Try and be honest, and then if they outdo your expectations that’s fantastic, but you’ve not given family that false hope.”* Junior SLT, Site 2
Q7	*“The SLT tells Adil that he is likely to have some continued problems with his speech upon discharge and that it might take months for this to get better.”* Family meeting fieldnotes, Site 2
Q8	*“So like with strokes, I think they’re just totally independent to people. I don’t think you can say a stroke’s going to last this long, it’s going to last that long.”* Carer, Site 1
Q9	*“The OT describes that, although there wasn’t really any evidence for this, when someone is motivated, their progression is quicker.”* Therapy session fieldnotes, Site 2
Q10	*“It’s just your own will wanting to get yourself better. Do stuff for yourself.”* Patient, Site 1
Q11	*“[They said] you can get there if you push yourself and do what you have to do, yeah.”* Patient, Site 1
Q12	*“I think we’re quite good at [.] talking about what’s realistic, so I suppose not giving them false hope [.] by saying yes you’ll get full use of that, your upper limb back, you’ll be able to do tasks normally.”* Junior PT, Site 2
Q13	*“The reality may not be what they would like to hear, but that’s the kind of specialty we work in. [.] it’s important they know that rather than you know, keeping up hopes and they crash outside in an unsupported environment, when they realise ‘hold on’ nothing what they thought will happen has happened.”* Consultant, Site 2
Q14	*“Peter appears tearful, and the PT says that recovery from a stroke is a ‘hard slog.’ She describes that compared with a few weeks ago, he is doing much better, as he previously didn’t have sitting balance and now his sitting balance and strength are, ‘so much better.’ [.] She says that he is ‘working so hard towards what he is going to be able to do’. The OT reiterates that he is ‘getting there’.”* Therapy session fieldnotes, Site 1
Q15	*“I think if somebody told me I was never going to walk again, I’d be like, ‘well what’s the point?’ [.] Sometimes it can have that effect.”* Experienced PT, Site 1
Q16	*“The consultant looks at Marion and describes how recovery from stroke is a long-term process; he summarises her prospects for recovery, stating that even in six months’ time, she probably won’t have made a full recovery. He stresses that they will work with her to give her the ‘maximum possibility’ of recovery.”* Family meeting fieldnotes, Site 2
Q17	*“I think it’s just reiterating and trying to almost say, well why don’t we try and get you as good as we can, and almost trying to look at the benefits a bit and focus on the stuff they can do and, rather than focus on the stuff what they might not be able to do.”* Experienced PT, Site 1
Q18	*“The PT describes how Bill currently requires lots of specialist help in therapy and so they are not looking at him going home soon. He says that when he does go home, Bill will probably need help from two people for walking. He goes on to say that Bill is doing ‘really well’ with his transfers, now only requiring help from two people. The community goal will be to transfer with help from one person.”* Family meeting fieldnotes, Site 2
Q19	*“Just how long will it take, that’s all I kept asking, how long will I be like this? But they just say, it’s just time, just time. And rest. And that’s it really.”* Patient, Site 1
Q20	*“Wife and daughter upset that [patient] has not had physiotherapy, and using tiredness as an excuse is not acceptable [.] I explained that resting and sleeping is part of the recovery.”* Patient record (Doctor), Site 1
Q21	*“We used to do meetings [.] on a need basis rather than a routine ‘let’s meet them early, kind of set the scene for where they’re heading’. [.] I always remember thinking these people have gone through six, seven, eight weeks of rehab, we’ve sat them down and said they’re not going to get much better or we’re heading in towards a plateau and it always came as a shock. Whereas I think now, we manage expectations better than we ever have.”* Experienced SLT, Site 2
Q22	*“They probably needed to be a bit more clearer as to why that review was happening [.] They need to be more explicit that it was for his care, not, ‘this is a discharge nurse and we’re going to chuck you out’, because I were in fear of that, when I went into the meeting, that, how am I going to manage with him, being hoisted.”* Carer, Site 1
Q23	*“This multidisciplinary meeting [.] should have been organised two or three times and [.] we’d come in and it turns out it hadn’t been organised and the doctor [.] or sister hadn’t been told or didn’t know it was happening, wasn’t in the diary.”* Carer, Site 1
Q24	*“I think if you asked questions, you got a straight answer, but I think if anybody didn’t bother to ask much, might not have found out all they ought to have known.”* Patient, Site 1
Q25	*“You can have it where there’s someone who is less experienced in stroke will come along and say, [.] ‘you’ll be fine, you know, you’ll be walking within four weeks’, and it’s like, ‘well they’re hoisted and really dense upper limb, they’ve got no sensory feedback at all in that side’ [.] different people tell people different things.”* Senior therapist, Site 1
Q26	*“The PT says he isn’t sure if they’ll ‘get there’ with [Patient]. [.] The SLT says she is dysarthric and has dysphagia, and she feels that “swallow-wise, she isn’t going to progress far”. [.] She describes that the best she will achieve is probably purée as her swallow is ‘very bad’. [.] The PT reiterates that since she started therapy, she has made ‘very small progress,’ and as they can’t give her exercises (due to her cognition), he isn’t sure if they can give her enough therapy to be effective.”* MDT meeting fieldnotes, Site 2
Q27	*“Normally we have a board meeting and [.] if we’ve had a bit of a difficult conversation with a family member because they’re not necessarily recognising what we’re recognising, say ‘heads up guys, I had a conversation with so-and-so’s wife or daughter and they don’t really understand what’s happened’.”* Junior PT, Site 2
Q28	*"The OT says that [Patient]’s equipment will be installed on Friday but there are still difficulties with his wife’s expectations; the OT says his wife ‘threw a wobbler’ when she began to discuss discharge [.] The consultant asks who has been managing this and the discharge coordinator replies that they have all been speaking to her. The consultant says the team need to set a firm discharge date to help manage her expectations.”* Board round fieldnotes, Site 2
Q29	*"The team discuss each patient in turn, focusing on current functional ability and discharge plans. There is very little discussion about what patients might achieve, excepting two patients who are engaging: for the first, the consultant suggests a nursing home might be suitable and for second, he comments that “we’re not going to get anywhere with him” and indicates the need to start discharge planning.”* Board round fieldnotes, Site 1
Q30	*“Discussion with [Patient] about stroke recovery and rehabilitation. Lots of reassurance given+ +.”* Patient record (Senior PT), Site 1
Q31	*“I think everyone’s fearful of the [.] your documentation needs to be accurate [.] I guess people worry where they stand legally if they say ‘right oh yeah, well by next week you’re going to be back doing the London marathon’, when actually they might be walking, but they’re going to have quite an impaired gait.”* Senior Therapist, Site 1
Q32	*"You can be sometimes be there queuing and queuing for a computer.”* Senior therapist, Site 1
Q33	*“I find that incredibly frustrating, so like we’ll be going into a review meeting and we’ll be thinking this patient isn’t [.] making a good recovery, and perhaps we need to be starting to talk to the family about that, but unless we get a few minutes with the doctor [beforehand], we’re relying on the fact that the doctors have read our notes and are on the same page, and there has been situations where the doctors have given a different viewpoint to what we were going to give. [.] so it’s either trampling over what’s already been said or kind of going along [with it] and that’s very difficult from a patient and family perspective to hear two different views.”* Senior therapist, Site 1
Q34	*“When the meeting ends, I speak to the OT. She tells me that this consultant is just “the worst one” to do these meetings, that he doesn’t know the patients well and she feels the story he told about a patient who recovered after a year just isn’t applicable to this patient, and this might have given his family ‘false hope’. She says the patient is slowly improving but isn’t the type of patient who will gain much further recovery.”* Family meeting fieldnotes, Site 2
Q35	*“I don’t think me head were right clever either, [.] it weren’t taking it in.”* Patient, Site 1
Q36	*“My sister came with me, so I’d get an understanding, because you can’t always hear what’s happening, can you? Initially.”* Carer, Site 1
Q37	*“Their family were adamant they were going to be walking before they went home. We said that’s probably not realistic and families are still, I think it’s sort of a grieving for what the patient once was but they just, it’s really difficult for them to take that information on board.”* Junior PT, Site 2
Q38	*“If it looks like they’re kind of not engaging, so looking for those social cues, like if everybody’s avoiding eye contact with you, if everybody’s kind of turned away from you, you know it’s not the right time because they’re not open to that kind of conversation.”* Experienced SLT, Site 2

(*continued on next page*)

Table 4 (*continued*)

Q39	*"There's some people that just want to know hard and fast rules, facts, figures about that patient. There's some people who say, "I'm never going to give up hope," and you have to be more careful around delivery and how much you deliver to them."* Experienced SLT, Site 2
Q40	*"I want to know what there is but I don't want to know too much if you know what I mean, because it's no good telling you something if you, I mean I've still got hope for me leg so, you know, so I'm going to keep hoping and trying."* Patient, Site 1
Q41	*"Consultant: I think you do tend to avoid it unless they ask specifically. So you wouldn't say, "I don't think you're going to walk again," unless they ask that question specifically. I don't think you would.* *Interviewer: Why?* *Consultant: Well, I think if it's important to the patient, I suppose it's almost like you're saying 'would I be able to get back to playing squash again' or 'would I be able to go on holiday again'. If they didn't ask those questions, you wouldn't necessarily answer it for them."* (Site 1)
Q42	*"I did, one day I didn't get upset about it or angry, I just thought, right they're busy, I wanted to talk to one of the nurses or one of the doctors about Mother's progress at the time, and they never got back to me. And I says, "Well, you know, visiting time's over, I have got to go", you know what I mean?"* Carer, Site 1
Q43	*"I suppose it's kind of a reflection of how the SLT team work on the stroke ward is we don't often see families because we tend to be up there for like the morning and then it's just the way that our caseload goes is that we tend to do our other wards in an afternoon, so we're not there for visiting."* Experienced SLT, Site 1
Q44	*"When a stroke victim's had a brain injury, he can't always relay what a doctor's said. So, really, it might have been an idea to have more consultations with us present."* Carer, Site 1
Q45	*"Sometimes if you can't meet the patient's relatives before or you can't see them before, [giving bad news] does come as quite a shock and I'd like to think as a team we manage that quite well but it's still very challenging."* Junior PT, Site 2
Q46	*"A lot of them are healthcare assistants and they don't know, and by the time a message gets to that person, and a message gets to that person, and a message gets to that, it gets lost. And it's quite frustrating, is that."* Carer, Site 1
Q47	*"I think it's really a shame that we don't have anywhere for people to go [when receiving bad news], especially when people are very upset. Like you will see [.] whole families that are just stood out in the corridor crying and everyone else is just walking past going about their day [.] I think it must be hard to be so upset just on the corridor for everyone to see."* Junior SLT, Site 2
Q48	*"Sometimes you're mindful that you're in the middle of a bay and you really don't want to deliver information around prognosis or recovery to them when there's ears everywhere, listening in."* Experienced SLT, Site 2
Q49	*"If you're on the ward there's too much going on and I don't think they'll take in what's happening anyway, what you're saying because there's so much other noise."* Experienced OT, Site 1

whose recovery had not met their expectations at discharge (and their carers) subsequently described disappointment and frustration, believing they had not received enough therapy and/ or tried hard enough. This was also reflected in patient records, which documented complaints about delivered amounts of therapy *(Q20)*.

3.2.2. A co-ordinated MDT approach enhances the frequency and consistency of communication about recovery

3.2.2.1. Approaching recovery conversations as an organised team improves provision. Although reported time pressures affected professionals' ability to provide information (particularly at Site 1, where the therapist: patient ratio was lower), they reported prioritising this important aspect of their work. However, the teams differed in their approaches, and the extent to which they organised and proactively offered this information to patients and families impacted their experiences *(O/I)*. At Site 2, the team adopted a shared and co-ordinated approach led by the consultant, with early and proactive information provision through routine family meetings, beginning ~a fortnight after admission and continuing at regular intervals. The team's work was organised to facilitate this, with a weekly session allocated to family meetings, and visible reminders to ensure equity. At early meetings, generic information was provided to prevent false hope; individualised predictions were shared later *(O/I)*. This structured process meant patients and carers had regular access to discussions with the team and knew when information was expected *(Q21)*.

In contrast, at Site 1 each discipline worked independently to provide information to patients with limited co-ordination (except between OT and PT) and leadership; such information primarily focused on progress achieved and vague, generic statements about the recovery process. Although collaborative information delivery through family meetings was seen as useful, the absence of a consistent approach meant meetings were not routinely offered to all patients, and observations revealed they were held infrequently and reactively, due to the need for decision-making, e.g., around discharge. This caused anxiety for invited patients and carers, who believed therapy would be withdrawn *(Q22)*. Discussions frequently focused on current functioning and progress, rather than future outcomes, unless questions were raised by attendees or information was required for decision-making. Meeting organisation was comparatively haphazard, resulting in negative experiences for some carers, who attended to find the required professionals were unavailable *(Q23)*. The absence of an organised approach meant that individualised recovery predictions were not routinely provided, and patients and carers perceived professionals lacked proactivity *(Q24)*.

3.2.2.2. Sharing of individualised predictions across the team is essential for consistent prognostic messaging about likely future function. In the MDT context, maintaining consistency in the prognostic messaging from different professionals could be challenging *(O/I/D)*. Some professionals described potential for contradictory messages to be delivered to patients and carers depending on the individual opinions of their treating professional. Differences in opinion could result from the uncertain trajectory, and/or the experience and skills of the professional making predictions *(Q25)*. Contradictions were felt to be confusing for patients and professionals were keen to avoid them by sharing their predictions across the team and reporting whether, when, and how information had been provided to patients (and their response).

At Site 2, this took place primarily through daily and weekly multidisciplinary meetings, which facilitated sharing of predictions about recovery and how these were communicated to patients and carers *(O/I; Q26/27)*. These issues were seen as central to discharge planning and therefore discussed predominantly during board rounds (which had this focus). There appeared a recognition that (1) sharing predictions could support collaborative multidisciplinary decision-making (e.g., discharge plans), and (2) that managing expectations about the extent of hospital-based recovery could lead to a smoother discharge, promoting acceptance of ongoing disability and encouraging collaboration between professionals, patients, and carers *(O/I*; *Q28)*.

At Site 1 however, board round and MDT meetings allowed only brief discussion of each patient, were medically led, and primarily structured around updates from each discipline (current treatment and functioning), with a focus on discharge planning. This emphasis meant that recovery predictions and how these had been received were rarely communicated *(Q29)*. Weekly therapy planning meetings allowed for some discussion of these issues but were attended only by OTs and PTs; wider dissemination appeared rare.

Professionals across sites reported how documenting predictions and conversations about recovery in patient records could facilitate sharing them with colleagues. The extent of such documentation was however variable, with a focus on only objective details of care *(I/D)*. Where discussions about recovery were documented, descriptions were vague *(Q30)*. Some therapists feared documenting predictions, due to the uncertain stroke trajectory and concerns about the consequences of inaccurate predictions *(Q31)*. Use of patients' documentation for communication also relied on professionals consulting their colleagues' entries; they reported this could be limited by insufficient time and computer access *(Q32)*. Such access was not permitted for social workers at either site, which could lead to potential inconsistencies when planning discharge *(I)*.

Inconsistencies could have negative consequences, causing discomfort for professionals and impacting patients' and carers' experiences and understanding *(O/I)*. Professionals particularly worried about family meetings and felt pre-meeting team communication was imperative to ensure consistent prognostic messaging. Where this did not occur and colleagues unexpectedly delivered information that was in contradiction to their own views, they worried this could cause confusion and delay adjustment, particularly where alternative opinions were felt to be over-optimistic (*Q33/34*).

3.2.3. Patients' and carers' abilities and needs impact provision of recovery information and their understanding of it

3.2.3.1. Patient and carer understanding influences professionals' decisions on timing, content and method of information delivery. Professionals' clinical reasoning about the amount, timing, and delivery of information about recovery was informed by a range of factors, which could impact whether patients and carers could effectively attend to, process, understand, and retain the information provided. For patients, these factors included cognitive changes, including reduced insight, and communication difficulties, which were also recognised by patients and carers as hindering their understanding *(Q35)*. Professionals, patients, and carers also described how the shock and distress caused by the overwhelming nature of stroke and its impact on functioning could impact patients' and carers' receipt of information *(Q36)*.

Where deeming a person unlikely to understand or retain information about recovery, professionals delayed its provision or considered how to adapt it to meet their needs. Described strategies included repeating information, providing it to carers rather than patients, or limiting the amount provided or number of people present to avoid overwhelming the recipient. Some discussed giving simple information about therapeutic activity and progress, rather than sharing predictions about likely future function (and the associated uncertainty). Despite acknowledging the potential benefits in aiding retention and patients describing its potential usefulness, written information was not regularly provided, primarily due to professionals' fears about the consequences of potential inaccuracies *(O/I)*.

Professionals also considered denial as a barrier to carers' acceptance of information, causing them to maintain hope for a full recovery, despite professionals' attempts to manage their expectations. Professionals understood this as grief for the patient's lost abilities and the ensuant life changes and spent time explaining and repeating information about the stroke's effects, recovery process, and potential outcomes, particularly where shared decision-making necessitated understanding *(Q37)*.

3.2.3.2. The importance of taking patients' and carers' wishes into account. Professionals across sites described making subjective judgements about patients' and carers' desire for information, considering patients' eye contact and body language when broaching the subject of recovery *(Q38)*. Whilst assuming that most wanted this information, they were aware some did not and described how rapport could aid clinical reasoning about how much to provide *(Q39)*. Most interviewed patients and carers described wanting this information; although one patient preferred not to receive it to preserve hope *(Q40)*.

The extent of patient and carer questioning was also considered by professionals, although few reported directly asking patients how much information they desired. Professionals described offering regular opportunities for questions; although a minority stated they would not proactively provide tailored predictions unless directly asked *(Q41)*. This reactive approach relied on patients' and carers' cognitive and communicative abilities and confidence, and available opportunities to approach professionals; this likely contributed to patients' and carers' perceptions that recovery information was not proactively provided at Site 1.

3.2.4. The stroke unit environment is not conducive to sensitive conversations about recovery

3.2.4.1. Hospital-based routines can limit opportunities for, and quality of, dialogue with carers. Hospital-based routines including visiting policies and working hours could impact carers' opportunities to interact with professionals *(O/I)*. Site 2 employed open visiting, which facilitated carers' engagement in rehabilitation; they could opportunistically approach professionals and join patients' therapy sessions. They were therefore privy to information provided to patients. Daytime visiting at Site 1 was however restricted to two hours in the afternoon, which limited carers' interactions with professionals *(Q42)*. Additionally, therapists typically worked standard hours (~08:30–16:30) on weekdays, with no weekend rehabilitation provided at either site; this limited access for carers who worked similar hours. SLT coverage at Site 1 was limited to mornings, further restricting carers' access *(Q43)*. Carers were therefore frequently reliant on patients to relay information provided in their absence; their reports could be affected by stroke-related cognitive and communication problems *(Q44)*.

The relative absence of opportunities for professionals and families to directly converse at Site 1 impacted both those providing and receiving information. Professionals felt it affected rapport-building, making it difficult to assess carers' information needs, and limiting their ability to prepare them for information delivered at formal family meetings, particularly where progress was slow *(Q45)*. For carers, particularly at Site 1, the impact was that their day-to-day interactions were limited to nursing staff, who were most readily available. Some however described how nurses provided little information about recovery, thus carers sometimes did not receive the information they needed, resulting in frustration *(Q46)*.

3.2.4.2. The right environment to talk about recovery?. Outside of formal family meetings, which were held in confidential spaces, quiet and private areas to discuss recovery were limited at both sites *(O/I)*. Most therapy sessions took place at the bedside or open gym; therapy kitchens, meeting rooms, and day rooms afforded more privacy, however they were few, and there was frequently competition to gain access. The absence of such areas occasionally resulted in information being provided in suboptimal environments and may have contributed to the relative absence of recovery predictions observed during therapy sessions. For example, a goal-setting session was observed in a noisy corridor with patients, staff, and visitors frequently passing, whilst the patient became emotional when discussing the limited likelihood of future progress with his OT.

Access to quiet and private space was deemed important by professionals for three reasons. Firstly, they acknowledged that they were delivering potentially life-changing information, which could provoke an emotional response, particularly where it involved bad news. The continued availability of private space following bad news delivery was also seen as important for recipients to digest the information *(Q47)*. Secondly, the information was deemed confidential, and it was therefore felt inappropriate to provide it where it could be overheard *(Q48)*. Thirdly, professionals described how noise and distractions, caused by, e.g., the radio/television or other conversations, could further impact recipients' ability to process the information *(Q49)*. In contrast, patients and carers rarely described the impact of the environment on their ability to receive information; they were simply grateful where it was provided.

4. Discussion and conclusion

4.1. Discussion

This study has identified factors impacting provision and receipt of information about recovery in stroke units, namely the uncertainty of the stroke trajectory, organisation of multidisciplinary communication, individual differences in patients' abilities and needs, and physical stroke unit environment and routines.

Most previous research has focused on provision of prognostic information by a single individual, usually a doctor [31]. This study extends existing knowledge by showing how the multidisciplinary nature of stroke care requires team collaboration to develop recovery predictions and share them with patients and carers. The involvement of a range of professionals with differing areas of expertise and experience levels increases the possibility for inconsistencies, which research demonstrates is a particular source of dissatisfaction and can result in confusion for patients and families [32–34]. Routine multidisciplinary communication is an important cornerstone of stroke unit care, and whilst it is recommended that teams meet at least weekly [20], there is little guidance about the nature and content of such communication and research has demonstrated that this is highly variable [35]. This study has demonstrated that regular and routine sharing of recovery predictions and patients' and carers' responses to them within such meetings can act to support clinical reasoning about information delivery and promote consistency in the messaging provided to patients, which could improve their experiences.

This study also advances the literature by demonstrating how patients' experiences of neurological symptoms, e.g., aphasia and cognitive impairment, can add complexity to professionals' decision-making around the communication of prognostic information, highlighting the need for tailoring of the content, delivery, and timing of provision according to individual needs. These symptoms are not unique to stroke, and findings are likely to have implications for the provision of prognostic information across neurological conditions. Their impact may however be particularly important in in-patient settings, where quiet and private spaces needed to facilitate understanding may be limited, and where patients' contact with their families is restricted, requiring them to relay information provided by professionals in their absence. This study has highlighted how opportunities for direct communication between professionals and carers can be limited by hospital and ward-based routines. Future research should consider how such routines can be optimised to increase opportunities for dialogue and carer involvement. For example, unrestricted visiting appeared effective in this study and has been perceived as beneficial to communication in other settings, such as older adult [36] and intensive care wards [37]; its effects however have not been formally explored in stroke care. Equally, extension of therapists' working hours, including the provision of seven-day rehabilitation services, is likely to increase opportunities, alongside other obvious benefits.

This study confirms findings from existing research, which report the concerns of professionals working in neurological rehabilitation about the potential effects of providing negative information about patients' recovery outlook on their motivation to engage in rehabilitation, and subsequently outcomes [15,17,19,25]. The nature of rehabilitation, requiring physical effort, means these concerns are pertinent in the stroke unit context, especially when compared to much of the existing prognostic communication literature, which typically relates to life-limiting conditions, e.g., cancer, where treatment compliance primarily requires adhering to medications. Given the typically upward trajectory of post-stroke recovery (again unlike areas where most prognostic communication research is focused), much of professionals' work relates to managing patients' and carers' expectations about the likely extent of recovery, whilst ensuring continued engagement. Research in stroke demonstrates that patients and carers generally hold higher expectations than do their therapists [38,39] and that there is potential for disappointment should these expectations not be realised, which is highly concerning for professionals [16]. The finding that vague and generic information is often presented to patients and carers echoes existing research from more than two decades ago [16]; this is in itself troubling, as such provision is unlikely to be effective in managing expectations, leading to potential disappointment and delayed adjustment. It is also noteworthy that where negative predictions were shared with patients in this study, this did not appear to impact rehabilitation engagement. This suggests that it is possible to share tailored information in ways that do not necessarily impact motivation; more research is however required to address this.

The uncertainty of the stroke trajectory is frequently viewed as a barrier to provision of individualised prognostic information [16]. Whilst such uncertainty is common, particularly in the early stages of recovery, this study has demonstrated how professionals apply their knowledge and clinical judgement to estimate the likely timing and extent of recovery for individual patients. It is important to note that such uncertainty is not exclusive to stroke; by its very nature, prognostication requires the prediction of unknowable future events. Whilst the literature facilitating predictions may be further developed in other clinical areas, prognostic research in stroke continues to advance, including the development of tools to support the process [40]. Despite this, challenges in applying these tools to individual patients remain, and will continue to require the communication of associated uncertainty to patients and carers [40]. Uncertainty has also been suggested as an opportunity for professionals, and can be utilised to support hope [21]. More research is however required to identify how best to convey this uncertainty, as well as how to improve professionals' confidence, particularly for nurses and therapists. Sharing learning from other clinical areas may help address this, e.g., guidelines in obstetric scanning recommend sharing a spectrum of possible outcomes [41]; a recently published study demonstrated how an intervention incorporating these guidelines increased sonographers' confidence [42].

Finally, our findings highlight how conversations about recovery continue to predominantly reflect the professionals' 'expert' viewpoint, with decisions about whether, when, and how to divulge personalised information frequently dependent on their views of its potential impact, rather than patients' and carers' individual needs and values. Previous studies have indicated that stroke survivors trust their treating professionals to make these decisions and rarely question them [43]. However, the move towards patient-centred care requires professionals to proactively identify patients' and carers' preferences for information to ensure their needs are met. As in previous research [44], this study has demonstrated that preferences can vary, although most prefer to receive information where available. Directly questioning patients about their needs has been recommended [45], but was not observed in this study, and could potentially be a simple way to identify needs, rather than relying on subjective judgements. Providing prompt lists of potential questions has also proven effective in eliciting patients' and carers' needs in other conditions [46,47].

To the authors' knowledge, this is the first study aiming to understand the factors influencing provision of recovery information in stroke units, and has strengths in the triangulation of professionals', patients', and carers' experiences and views of providing and receiving information about recovery, which have rarely been contemporaneously explored in in-patient stroke care using observations, interviews, and documentary analysis. The unique application of an ethnographic approach to exploring prognostic communication facilitated investigation of the problem from different perspectives and provided insights into the world of practice that stroke professionals are present in but rarely fully conscious of, in terms of evaluating what influences their actions and the extent to which their perceptions are consistent with their behaviour. These insights would not have been possible in most studies of prognostic communication, which tend to rely on a single data source.

Nevertheless, some limitations must be acknowledged, including the use of a single researcher to collect data. Although traditional in ethnographic approaches, researcher bias could have influenced study conduct, e.g., the focus of observations and questioning. However, reflexivity was employed through which the researcher actively and consciously considered her impact throughout the research process, including through maintaining a reflexive diary. Although one researcher was involved in the primary analysis of data, frequent discussion with the wider research team enabled the challenging of emerging interpretations and findings. The sampling of only two stroke units could also be considered a limitation, although purposive sampling enabled selection of sites which were generally representative of UK-based stroke units, and which differed significantly in their approach to provision of recovery information. Contextual detail has been provided to enable readers to assess the transferability of findings, and whether they apply to other healthcare systems, where stroke care is organised differently. Additionally, due to the impact of the COVID-19 pandemic towards the end of the study, most formally interviewed patients attended Site 1; the views of those from Site 2 are thus under-represented in this dataset. However, observational data (including from informal conversations with participants who were not interviewed) contributed to the final analysis, enabling their views to be captured. The relatively small number of participating nurses is also a limitation, and their roles require further investigation, as do those of more peripheral team members, e.g., dieticians and orthoptists. Nevertheless, the sample of professionals was generally representative of the core stroke unit MDT.

4.2. Conclusion

Employing a focused ethnographic case-study design including non-participant observations of stroke unit practice, semi-structured interviews with professionals, patients, and carers, and analysis of documentary evidence has facilitated in-depth exploration of the factors influencing provision and receipt of information about post-stroke recovery. These factors include the uncertainty of the stroke trajectory, organisation of multidisciplinary communication, individual differences in patients' abilities and needs, and the physical stroke unit environment and routines.

4.3. Practice implications

These findings highlight the importance of engaging patients and carers in dialogue to understand their information needs and identify how they might best be met; further targeted training for professionals is likely to be necessary to ensure they have the required skills. Improved organisation of the processes for delivering such information is likely to result in greater equity, ensuring that all patients and carers are provided opportunities to discuss the effects of stroke and likely extent and timescales for recovery, which could facilitate adjustment and engagement in decision-making. Multidisciplinary collaboration in sharing both predictions about recovery and patients' and carers' responses to them is key to increasing consistency in prognostic messaging and identifying where further information is required, which could improve experiences and reduce complaints.

Ethical approval

Ethical approval was obtained from the Health Research Authority (Yorkshire & the Humber (Bradford-Leeds) NHS Research Ethics Committee Ref: 19/YH/0009).

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CRediT authorship contribution statement

David J Clarke: Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Sarah F Tyson:** Writing – review & editing, Supervision, Funding acquisition, Conceptualization. **Thomas F Crocker:** Writing – review & editing, Supervision, Methodology. **Judith Johnson:** Writing – review & editing, Supervision. **Anne Forster:** Writing – review & editing, Supervision, Funding acquisition. **Louisa-Jane Burton:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Louisa-Jane Burton reports financial support was provided by The Stroke Association. Louisa-Jane Burton, Anne Forster, Thomas F Crocker report a relationship with Leeds Hospitals Charity that includes: funding grants. Anne Forster and Thomas F Crocker declare the following activity which may be considered a potential competing interest: authorship of the Cochrane review 'Information provision for stroke survivors and their carers'. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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