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# BMJ Open

## Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: A systematic review of qualitative literature

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**Experiences and views of receiving and delivering information about recovery in  
acquired neurological conditions: A systematic review of qualitative literature**

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**ABSTRACT**

**Objective:** To review and synthesise qualitative literature relating to the views, perceptions and experiences of patients with acquired neurological conditions and their caregivers about the process of receiving information about recovery; as well as the views and experiences of healthcare professionals involved in delivering this information.

**Design:** Systematic review of qualitative studies

**Data sources:** MEDLINE, Embase, AMED, CINAHL, PsycINFO, Web of Science, and the Cochrane library were searched from their inception to July 2019.

**Data extraction and synthesis:** Two reviewers extracted data from the included studies and assessed quality using an established tool. Thematic synthesis was used to synthesise the findings of included studies.

**Results:** Searches yielded 9,105 titles, with 145 retained for full-text screening. Twenty-eight studies (30 papers) from eight countries were included. Inductive analysis resulted in eleven descriptive themes, from which five analytical themes were generated: The right information at the right time; Managing expectations; It’s not what you say, it’s how you say it; Learning how to talk about recovery and manage emotions; The context of uncertainty.

**Conclusions:** Our findings highlight the inherent challenges in talking about recovery in an emotional context, where breaking bad news is a key feature. Future interventions should focus on preparing staff to meet patients’ and families’ information needs, as well as ensuring they have the skills to break bad news compassionately and share the uncertain trajectory characteristic of acquired neurological conditions. An agreed team-based approach to talking about recovery is recommended to ensure consistency and improve the experiences of patients and their families.

## ARTICLE SUMMARY

### Strengths and limitations of this study

- This is the first systematic review of findings from qualitative studies exploring discussions about recovery in the context of acquired neurological conditions, which has integrated and contrasted the experiences and perspectives of patients, their caregivers and healthcare professionals.
- Developing an understanding of the experiences and perceptions of patients, caregivers and healthcare professionals through systematic synthesis of qualitative literature using rigorous methods can inform the development of interventions to improve practice.
- Due to the diversity of language used in the field of talking about recovery and breaking bad news, it is possible that we did not identify all titles meeting our inclusion criteria; however, all efforts were made using broad search criteria and backwards and forwards citation searching.

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**BACKGROUND**

A number of acquired conditions can cause damage to the brain, spine or peripheral nervous system, including traumatic injury, stroke and haemorrhage, with over a million survivors living in the UK alone.[1] Such disorders have a sudden onset, and if survived, can result in impairments to movement, sensation, cognition, and communication, with the potential for wide-ranging effects on an individual’s daily life. For many survivors, the road to recovery is long, and rehabilitation provided by a multidisciplinary team of doctors, nurses and therapists is recommended.[2-5]

The long-term impact of these events is characterised by uncertainty,[6] and as they participate in rehabilitation, survivors often have questions about the possibility of returning to their previous lifestyles. Such questions prompt conversations about recovery, which may involve healthcare professionals (HCPs) making and conveying predictions about recovery potential and sometimes breaking bad news.[7] Bad news has been defined as “any information that produces a negative alteration to a person's expectations about their present and future” pp. 312.[8] The term is often applied in cancer and palliative care, in relation to a life-limiting prognosis. In neurological settings however, these conversations have a somewhat different focus: some recovery is often possible and discussions may relate to whether an individual will regain functions such as movement or continence, be independent in daily life and return to activities they enjoy, or participate in their vocational or social roles. Discussions may be complicated by the inherent uncertainty in neurological recovery, and the potential impact of cognitive or communication difficulties resulting from these conditions, which can require information to be presented in different formats and increased involvement from patients’ families.[7] Despite these challenges, information about recovery is important for individuals to make future plans, and potentially adjust to life with long-term disability.

As the science in predicting recovery develops,[9-11] researchers have increasingly sought to explore and understand discussions about recovery from the perspectives of those who have experienced them, namely the patients and caregivers receiving information and the HCPs who provide it (e.g.[12]). The use of qualitative methods has generated rich and detailed understanding across a variety of contexts following diagnosis of acquired neurological conditions. However, studies are often small, condition-specific and focus on a single group (patients, caregivers, or HCPs). Synthesis of qualitative literature facilitates translation of concepts across a range of studies, making their findings accessible to a wider audience and informing clinical practice and policy.[13] This review aims to bring together and synthesise findings from qualitative studies across acquired neurological conditions, including stroke, traumatic brain injury (TBI), spinal cord injury (SCI) and brain tumour, where similar issues may be encountered, to understand how conversations about recovery are viewed and experienced by patients, their families and HCPs involved in their care. Synthesis of participants' views and experiences from this review will inform development of an intervention to improve conversations about recovery after stroke.

## **METHODS**

The systematic review protocol was prospectively registered on the International Prospective Register of Systematic Reviews (PROSPERO ref: CRD42017081922).

### **Search strategy and data management**

Electronic databases including MEDLINE, Embase, AMED, CINAHL, PsycINFO, Web of Science and the Cochrane library, were searched from time of inception to end of July 2019.



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A search strategy was developed with assistance from an Information Specialist (see Supplementary File 1 for an example search). Studies were eligible if they were published in English language and:

- Reported empirical qualitative research;
- >50% of participants were either adults with a diagnosis of an acquired neurological condition (stroke, TBI, SCI, brain/central nervous system tumours), their caregivers or HCPs;
- Reported experiences, views or perceptions of giving and/ or receiving information about prognosis or recovery.

There were no restrictions according to setting or time post-diagnosis.

Previous authors of systematic reviews aiming to identify papers relating to the provision of recovery information and breaking bad news have identified challenges in keyword searching, resulting from the variety of language used in this field,[14] for example, “prognostic awareness”[15] or “difficult conversations.”[16] We aimed to be as comprehensive as possible in our selection of keywords and, to ensure literature saturation, employed backwards and forwards citation searching of included articles.

Literature search results from each database were combined, and de-duplicated in EndNote. Titles and abstracts were screened for eligibility against the inclusion criteria, with 20% independently screened by a second reviewer. Full texts were obtained for each paper deemed to meet inclusion criteria and for those where there was uncertainty. Full text review was conducted by two independent reviewers using a Microsoft Access database, where reasons for exclusion were recorded. Discrepancies between reviewers were discussed and referred to a third reviewer where agreement could not be reached.

## Quality appraisal

Critical appraisal of study quality was completed using a checklist covering the core domains of quality in qualitative research (the NICE public health guidance quality appraisal checklist[17]), which assesses fourteen domains including study design and appropriateness of qualitative methods, clarity of the study aims, data collection methods including triangulation, consideration of context, the role of the researcher, analytical methods, conclusions and ethics. Included studies were graded in three categories according to whether all or most of the checklist items were fulfilled (++), some of the items were fulfilled (+), or few or none of the items were fulfilled (-).

Two independent reviewers scored each included study according to the checklist. The primary reviewer compared both sets of scores and discussed areas of disagreement with the second reviewer. Where consensus could not be reached, a third reviewer was consulted. In this study, quality was assessed to reveal possible limitations to included studies, rather than for the purposes of exclusion. This was to ensure that the results would not be biased by lower quality studies and therefore lower the risk of drawing unreliable conclusions.

## Data extraction and synthesis

Data were extracted from the selected papers, using a standardised form. Extracted data included study aims, sampling techniques and size, participant demographic information (age, gender, diagnosis), country, study setting, and methodology (data collection and analysis methods). Data were extracted from all included studies by two independent reviewers and compared to check agreement levels.

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In addition, all text labelled as ‘results’ or ‘findings’, including participant quotations and author-generated analytical themes was extracted from included studies into qualitative data management software (QSR NVivo v10). Thematic synthesis[13] was selected for this study because it can be applied to review questions aiming to make recommendations for interventions,[18] and moves from initial line-by-line coding of data presented in individual studies, to subsequent development of descriptive, and then analytical, themes. Its detailed procedure addresses questions relating to transparency in qualitative synthesis by maintaining a clear link between the findings of primary studies and the review conclusions.[13]

In this study, extracted data were inductively free-coded line-by-line. The codes generated were grouped and organised into descriptive themes to form a coding framework, which was subsequently reapplied to the included studies. The coded findings were then displayed in a framework matrix, to facilitate comparison of the views and experiences of HCPs, patients and caregivers; and to assess whether and how views and experiences might vary, depending on neurological condition and participant type. Summaries describing what was important to patients, caregivers and HCPs when talking about recovery were developed for each descriptive theme and the findings of the primary studies were then considered against the review questions to develop analytical themes. This involved interpretation of study findings to develop an understanding of the range of issues that are important to participants when talking about recovery and how these affect behaviour, to make recommendations for the development of a future intervention. This development was iterative and founded upon links between the identified descriptive themes and their implications for how patients, caregivers and HCPs experience the provision and receipt of information about recovery. A final stage of reading through all included studies ensured that findings were representative of the original studies.

## Patient and Public Involvement

Members of the Leeds Consumer Research Advisory Group, and two Stroke Association-run groups in Greater Manchester were involved in the design of the studies making up this programme of research and supported the proposals for the design and conduct of this review.

## RESULTS

Following removal of duplicates, the searches identified 9105 articles for title/ abstract screening (see Figure 1). Full texts of 145 papers were retrieved for review, and 30 papers reporting 28 studies were retained for inclusion. Two studies were reported in two papers each: Lefebvre & Levert[19, 20] and Wiles et al[21, 22].

[Figure 1 about here]

### Study characteristics

The 28 included studies were conducted in eight different countries: Nine in the USA,[15, 23-30] six in the UK,[12, 16, 22, 31-34] five in Australia,[35-39] three in Canada,[40-42] two in Italy,[43, 44] one each in Sweden[45] and Turkey,[46] and one in Canada and France[19, 20] (see Table 1). Most studies came from the stroke literature (n=10),[22, 23, 26, 31, 32, 34-36, 39, 45] whilst similar numbers came from TBI (n=6),[19, 20, 24, 25, 28, 29, 42] SCI (n=5),[27, 40, 43, 44, 46] and general neurology (n=5),[12, 16, 33, 37, 41] with a minority from the brain tumour literature (n=2).[15, 38] Roughly equal numbers took place in the in-patient setting (n=10)[15, 16, 23, 24, 28-31, 40, 45] and community (n=11),[25-27, 32, 35, 36, 38, 39, 42, 44, 46], whilst a minority took place across multiple settings: in-patient and out-patient (n=2),[22, 34, 41] in-patient and community (n=3),[12, 19, 20, 43] and two included HCPs from a range of settings, including in-patient, out-patient and community[33,

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37]. Of note, two studies were conducted in palliative care settings; one involved neurological conditions,[41] the other involved TBI.[29]

Five studies included data from only individuals with the condition,[27, 35, 39, 44, 46] four reported views of only caregivers,[15, 24, 30, 43] and four included perspectives of both individuals with the condition and caregivers.[25, 26, 36, 38] Seven included only HCPs, including physiotherapists,[33] occupational therapists,[12] speech and language therapists,[37] nurses,[40] doctors and nurses,[45] or a mixture of therapists,[32] or a wider mix of HCPs.[16] Three included individuals with the condition and HCPs,[22, 23, 31, 34] one included caregivers and HCPs,[28] and four included all three groups.[19, 20, 29, 41, 42] Participant demographic data from the included studies are presented in Tables 2 and 3.

In terms of data collection, most studies used semi-structured interviews (n=17),[12, 23, 24, 26, 28-30, 33, 36-39, 42-46] and three used focus groups.[19, 20, 25, 35] One used a survey,[27] and one analysed a video-taped observation.[31] Seven used mixed-methods: three employed focus groups and interviews;[16, 40, 41] one each used interviews and questionnaires,[15] observations and interviews,[22, 34] and a questionnaire and observations.[32]

Table 1: Characteristics of included studies

Authors	Neurological condition	Stated aim	Country	Service setting	Perspective	Sampling method	Sample size	Time after event	Data collection	Methodology/ Data analysis	Quality rating
Applebaum et al	Brain tumour	To understand what informal caregivers of patients with malignant glioma understand about their loved one's prognosis, how they derived this information, what additional information they would like, and the existence of discrepancies in prognostic understanding between informal caregivers and patients with malignant glioma.	USA	Inpatient Neurology service at a Cancer Centre	Caregiver (Patient)	Not stated	32 (32)	In-patient	Mixed - methods. Interviews and follow-up questionnaire	Inductive thematic textual analysis	-
Becker & Kaufman	Stroke	To examine illness trajectories from two vantage points, that of older persons who have had a stroke and that of physicians who care for stroke patients	USA	Community hospital	Patient Healthcare Professional	Not stated Snowball	36 20	In-patient	Semi-structured interviews	Content analysis	+
Bond et al	TBI	To discover the needs of families of patients with severe traumatic brain injury during the families' experience in a neurosurgical ICU	USA	Neurological ICU	Caregiver	Convenience	7	In-patient	Interviews	Content analysis	+
Ch'ng et al	Stroke	To explore long term perspectives on coping with recovery from stroke, to inform the design of psychological interventions.	Australia	Stroke support groups	Patient	Purposive	26	Community 6 months-years	Focus groups	Thematic analysis	+
Conti et al	SCI	To explore the experience of caregivers of individuals with SCI analysing the final phase of hospitalization and at 6 months from discharge, to highlight their needs during hospitalization as well as emotional experiences, reactions to difficulties resulting from being back home, and subsequent positive and negative aspects related to discharge.	Italy	SCI unit	Caregiver	Purposive	11	In-patient and community	Interviews	Phenomenology: Giorgi method	++
Dams-O'Connor et al	TBI	To learn about the experiences individuals with BI have in seeking and accessing healthcare (both primary and speciality care), from the 'patient' or insider perspective, in order to better understand how providers and health systems can improve care for their patients with BI	USA	Medical centres and support groups	Patient Caregiver	Convenience	44 1	Community 0.8-66.3 years	Focus groups	Content analysis	+
Danzl et al	Stroke	To examine rural Appalachian Kentucky stroke survivors' and caregivers' experiences of receiving education from health care providers with the long-term goal of optimizing educational interactions and interventions for an underserved population	USA	Discharged patients from medical centres and rehab network (flyers/ mailshot)	Patient Caregiver	Convenience*	13 12	Community 1-14 years	Semi-structured interviews	Content analysis	+
Dewar	SCI	To explore nurses' perceptions of their role in delivering bad news in an acute spinal cord injury unit and to describe their	Canada	Acute spinal cord unit	Healthcare professional	Convenience*	22	In-patient	Focus groups, 1 interview	Grounded theory – constant comparison method	-

		experiences, difficulties, and needs as professionals.									
El Masry et al	Stroke	To explore the psychosocial aspects of the experiences, concerns, and needs of caregivers of persons following stroke.	Australia	Discharged patients from neurology unit, speech therapy department and rehab hospital	Patient  Caregiver	Purposive (maximum variation and theoretical sampling)	10  20	Community >3 months	Semi-structured interviews	Interpretive phenomenological analysis: Thematic analysis	++
Garrino et al	SCI	To assess SCI patients' perception of care by collecting important data to improve the current hospital and rehabilitative model of care	Italy	Discharged patients from SCU	Patient	Purposive*	21	Community >3 months post-discharge	Semi-structured interviews	Narrative approach: Content analysis	-
Gofton et al	Neurological conditions	To develop a conceptual understanding of the specific characteristics of palliative care in neurology and the challenges of providing palliative care in the setting of neurological illness.	Canada	Academic medical centre	Patient  Caregiver  Healthcare professional	Not stated  Not stated  Purposive	Not stated	In-patient and Out-patient palliative	Dyadic patient/caregiver interviews  Focus groups	Grounded theory – constant comparison method	+
Grainger et al	Stroke	To explore the practice of bad news delivery in a specific healthcare setting.	UK	Stroke rehabilitation ward	Patient  Healthcare Professional	Not stated	1  1 (part of larger study)	In-patient rehabilitation	Video-recorded interaction	Ethnography: Conversation analysis	-
Hersh	Neurological conditions	To discuss speech pathologists' reports about how they discharge their clients with chronic aphasia; to explore the process of weaning in order to define its nature and raise awareness of it as a common aspect of clinical practice.	Australia	Practicing SLTs	Healthcare Professional	Not stated	20	In-patient/ Out-patient and community	Semi-structured interviews	Grounded theory	-
Kirshblum et al	SCI	To determine when, by whom, and in what setting persons with neurologically complete traumatic SCI want to hear of their prognosis.	USA	Medical rehabilitation facilities	Patient	Convenience	56 (45 completed qualitative component)	Community >3 months	Online survey with open and closed questions	Thematic analysis	-
Lefebvre et al	TBI	To investigate the experiences of individuals who had sustained a TBI, their families, the physicians and health professionals involved, from the critical care episodes and subsequent rehabilitation.	Canada	Hospital rehabilitation centres; paramedical organisation and victims association	Patient  Caregiver  Healthcare professional	Purposive (Maximum Variation Sampling)*	8  14  36	Community mean 2.8 years	Semi-structured interviews	Thematic analysis*	+
Lefebvre & Levert**	TBI	To explore the needs of individuals and their loved ones throughout the continuum of care and services, from the point of view of everyone affected by the experience of a TBI. including individuals, their loved ones, and the health care professionals involved in their care.	Canada and France	Not stated  Not stated  Acute care, rehabilitation	Patient  Caregiver  Healthcare professional	Convenience	56  34  60	Community mean=4.3 years  In-patient/ community	Focus groups	Thematic content analysis	+



				or social reintegration							
Lobb et al	Brain tumour	To understand patient experiences of high grade glioma and to describe their information and support needs.	Australia	Tertiary centre for neurological cancers	Patients Caregivers	Purposive	19 21	Community within 1 year of diagnosis	Semi-structured interviews	Grounded theory – constant comparison method	+
Maddern & Kneebone	Stroke	To explore the experience of stroke survivors when receiving bad news (RBN) from medical practitioners	Australia	Community stroke clubs	Patients	Convenience*	10	Community 2-4 years, mean=6.2 years	Semi-structured interviews	Interpretive phenomenological analysis, Thematic analysis	+
Ozyemisci-Taziran et al	SCI	To investigate the process of breaking bad news from the perspective of spinal cord injury survivors.	Turkey	Discharges from in-patient rehabilitation	Patients	Not stated	14	Community 1-19 years, mean=7.5 years	Semi-structured interviews	Content analysis	-
Peel et al	Neurological conditions	To explore health professionals' lived experiences of having difficult conversations surrounding rehabilitation potential; to explore different strategies used to support these difficult conversations; and to identify how future practice could be improved.	UK	Regional neurorehabilitation unit within an acute hospital	Healthcare professional	Convenience*	15	In-patient	One focus group; 5 individual interviews	Phenomenological approach: Thematic content analysis	+
Phillips et al	Stroke	To address the seemingly neglected area of BBN within stroke care, by documenting a collaborative consultation undertaken to support this skill within a multidisciplinary community stroke rehabilitation team	UK	Multidisciplinary community stroke team for early discharge	Healthcare Professional	Self-selecting*	5	Community	Case study of consultation. Self-report questionnaire, qualitative observations	Not stated	-
Quinn et al	TBI	To explore key communication preferences and practices by stakeholders (surrogates and physicians) for the outcome prognostication during goals of-care discussions for critically ill TBI patients	USA	Level-1 trauma centres	Caregiver Healthcare Professional	Purposive Purposive and snowball	16 20	In-patient	Semi-structured interviews	Content analysis	+
Rejno et al	Stroke	To deepen the understanding of stroke team members' reasoning about truth telling in end-of-life care due to acute stroke with reduced consciousness	Sweden	Combined acute and rehabilitation stroke unit teams	Healthcare Professional	Convenience sample	15	In-patient	Interviews	Content analysis	++
Schutz et al	TBI	To explore how family members, nurses, and physicians experience the palliative and supportive care needs of patients with severe acute brain injury receiving care in the neuroscience intensive care unit	USA	Neuro-ICU	Patient Caregiver Healthcare Professional	Purposive	15 16 31	In-patient palliative care	Semi-structured interviews	Thematic analysis	++
Sexton	Neurological conditions	To answer the question, 'What are the experiences of occupational therapists when having bad news conversations with disabled people regarding long-term neurological disability?'	UK	Neurological OTs	Healthcare professional	Convenience	10	In-patient and community	Semi-structured interviews	Phenomenology: Thematic analysis*	++
Soundy et al	Neurological conditions	To 1) explore the meanings of the different types of hope that neurological physiotherapists give to patients to consider, 2) give greater depth to the role of hope in clinical practice, 3) present the	UK	Neurological physiotherapists	Healthcare Professional	Purposive	9	In-patient, out-patient and community Clinical	Semi-structured interviews	Categorical-content analysis	++



		dilemmas of physiotherapists hope for their patient, and 4) illustrate how different disease prognoses may influence hope						specialists and educators in one UK city			
Wiles et al***	Stroke	To explore the factors, associated with physiotherapists' provision of information, that may contribute to patients' high expectations of physiotherapy	UK	3 acute Trusts	Patient Healthcare Professional	Not stated	16 26	In-patient and out-patient	Longitudinal case studies – semi-structured interviews and observations	Grounded theory: Thematic analysis	++
Zahuranec et al	Stroke – intracerebral haemorrhage	To examine surrogate decision maker perspectives on provider prognostic communication after intracerebral haemorrhage	USA	5 health system/ hospital/ medical centre sites	Caregiver (Patient)	Convenience*	52 (52)	In-patient: Median day from admission to interview = 35.5	Semi-structured interviews	Thematic analysis*	+

ICU=Intensive Care Unit; TBI=Traumatic Brain Injury; SCI=Spinal Cord Injury; OT=Occupational Therapist. Participants in parentheses were recruited to the study but did not participate in the qualitative element, therefore results from these participants have not been included in the analysis. \*Inferred from author's description; \*\* A second paper from the same study was also used in the analysis, which considered only the Canadian data from healthcare professionals (n=29) and caregivers (n=19); \*\*\*A second paper from the same study was also used in the analysis, which considered the process of discharge and included only the patients who had completed data at the third time=point (n=13 patients and n=21 healthcare professionals)

Table 2: Included studies, patient and carer demographics

Authors	Perspective	Sample size	Age range	Mean age	% female
Applebaum et al	Caregiver	32	Not stated	Average=50	64
Becker & Kaufman	Patient*	36	48-105	Not stated	64
Bond et al	Caregiver	7	41-61	Not stated	71
Ch'ng et al	Patient	26	22-79	60.9	54
Conti et al	Caregiver	11	28-80	57.4	73
Dams-O'Connor et al	Patient	44	23-72	Not stated	58
	Caregiver	1	Not stated	Not stated	Not stated
Danzl et al	Patient	13	42-89	63.4	69
	Caregiver	12	38-75	55.9	58
El Masry et al	Patient	10	41-50=2; 61-70=4; 71-80=3; 81-90=1	Not stated	20
	Caregiver	20	31-40=2; 41-50=2; 51-60=3; 61-70=5; 71-80=5; 81-90=3	Not stated	80
Garrino et al	Patient	21	34-63 (F); 19-70 (M)	Not stated	24
Gofton et al	Patient*	Not stated	Not stated	Not stated	Not stated
	Caregiver	Not stated	Not stated	Not stated	Not stated
Grainger et al	Patient*	2 (part of larger study)	Not stated	Not stated	100
Kirshblum et al	Patient	56 (45 completed qualitative component)	18-30=10 31-40=17 41-50=17 50+=12	Not stated	13
Lefebvre et al	Patient*	8	18-29=5, 30-39=1, 40-49=2	28.4	25
	Caregiver	14	18-29=3; 30-39=3; 40-49=4; 50-59=10; 60+=2	46.4	64.3
Lefebvre & Levert*	Patient*	56	Not stated	Not stated	30
	Caregiver	34	Not stated	Not stated	59
Lobb et al	Patients	19	Not stated	Not stated	37
	Caregivers	21	30-39=2; 40-49=2; 50-9=10; 60-69=6; 70+=1	Not stated	81
Maddern & Kneebone	Patients	10	61-84	63.4	30
Ozyemisci-Taziran et al	Patients	14	25-57	37.2	7
				Median=35.5	
Quinn et al	Caregiver*	16	Not stated	57	56
Schutz et al	Patient*	15	Not stated	46.1	33
	Caregiver	16	Not stated	Not stated	69
Wiles et al**	Patient*	16	41-79	66	62.5
Zahuranec et al	Caregiver	52	Not stated	Median=55	60

\*A second paper from the same study was also included, with 19 caregivers, age range=28-67, mean 50.6 years; \*\*A second paper from the same study was also included, with 13 patients of the same age range/mean age, 61.5% female.

\*Study also included healthcare professionals (see Table 3)

Table 3: Included studies, Healthcare professional demographics

Authors	Perspective	Sample size	Professional roles	Age range	% female	Years of experience in practice	Years of experience with condition
Becker & Kaufman	Healthcare Professional	20	Physicians	32-78	20	Not stated	Not stated
Dewar	Healthcare professional	22	Nurses	22-54	Not stated	Mean=7.4	Mean=4.6
Gofton et al	Healthcare professional	Not stated	Physicians 5 nurses 6 allied health professionals (SLT, OT, PT)	Not stated	Not stated	Not stated	Not stated
Grainger et al	Healthcare Professional	1 (part of larger study)	OT	Not stated	100	Not stated	Not stated
Hersh	Healthcare Professional	20	SLT	Not stated	97	>20 = 12; 5-20 = 14; <5 = 4	Not stated
Lefebvre et al	Healthcare professional	36	Nurse=16.1%; PT=9.7%; OT=6.5% SLT=3.2%; Remedial teacher=3.2%; Psychologist=6.5%; Social worker=12.9%; Special educator=6.5%; Psychosocial coordinator=3.2%; Physician=29%	Not stated	Not stated	Mean=12 <5=16.1%; 6-10=19.4%; 11-15= 35.5%; 16-20=25.8%; >20 = 6.2%	Mean=8.2 <5=32.3%; 6-10=32.3%; 11-15=25.8%; 16-20=9.7%
Lefebvre & Levert*	Healthcare professional	60	13 psychology/ neuropsychology; 7 OT 6 social work; 5 nursing; 4 health care aid; 3 PT; 2 kinesiology; 2 SLT; 2 clinical coordination; 2 rehabilitation counselling	Not stated	68.3	Average= 15.75	1-30

Peel et al	Healthcare professional	15	Physicians, nurses, OT, PT, SLT, psychologists	Not stated	80	Not stated	<1=5, >10 years=4
Phillips et al	Healthcare Professional	5	2 OT, 1 PT, 1 SLT, 1 rehabilitation assistant	Not stated	100	8-38	Not stated
Quinn et al	Healthcare Professional	20	Physicians	Mean age=47	35	Not stated	Median (speciality practice)=11, range=2-40
Rejno et al	Healthcare Professional	15	4 physicians, 11 nurses	Mean age=48	73	Not stated	Median: 11
Schutz et al	Healthcare Professional	31	Physicians Nurses	Not stated Mean age=44.7	19 80	Median=4 Median=18	Not stated
Sexton	Healthcare professional	10	OT	21-30=3, 31-40=5, 41-50=2	90	11 (range=2-27)	6.9 (range=1-13)
Soundy et al	Healthcare Professional	9	PT	Mean age=43.2	100	Not stated	4-17 (median=10)
Wiles et al**	Healthcare Professional	26	PT	Not stated	Not stated	Not stated	Not stated

SLT=Speech and Language Therapist; OT=Occupational Therapist; PT=Physiotherapist; \*A second paper from the same study was also included, with 29 healthcare professionals of the same professions, average experience in rehabilitation=13 years, no other demographics available. \*\*A second paper from the same study was also included, with 21 PT, no other demographics available.

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**Quality assessment**

Table 4 details the methodological quality of included studies. Most (n=20) were scored + or ++, suggesting that all/ most or some of the criteria were met, and where there was insufficient description the conclusions would be unlikely to change. Of the eight studies deemed to be of lower quality, four lacked richness of the data presented.[26, 27, 44, 46] In four, the context from which the data were drawn was unclear,[32, 37, 40, 41] and in three, the analysis did not appear sufficiently rigorous.[32, 40, 46] In three studies, research methodology was not adequately justified,[31] data collection methods were not clearly described,[31] methods were felt to be unreliable,[40] or the links between the findings and conclusions were unclear.[27]

Table 4: Methodological quality of included studies

	<i>Appropriate</i>	<i>Not sure</i>	<i>Inappropriate</i>
<b>1 Theoretical approach: appropriateness</b>	28	0	0
	<i>Clear</i>	<i>Mixed</i>	<i>Unclear</i>
<b>2 Theoretical approach: clarity</b>	24	4	0
	<i>Defensible</i>	<i>Not sure</i>	<i>Indefensible</i>
<b>3 Research design/ methodology</b>	10	17	1
	<i>Appropriately</i>	<i>Not sure/ Inadequately reported</i>	<i>Inappropriately</i>
<b>4 Data collection</b>	14	13	1
	<i>Clearly described</i>	<i>Not described</i>	<i>Unclear</i>
<b>5 Trustworthiness: role of the researcher</b>	4	24	0
	<i>Clear</i>	<i>Not sure</i>	<i>Unclear</i>
<b>6 Trustworthiness: context</b>	15	9	4
	<i>Reliable</i>	<i>Not sure</i>	<i>Unreliable</i>
<b>7 Trustworthiness: reliable methods</b>	7	20	1
	<i>Rigorous</i>	<i>Not sure/ not reported</i>	<i>Not rigorous</i>
<b>8 Analysis: rigorous</b>	16	9	3
	<i>Rich</i>	<i>Not sure/ not reported</i>	<i>Poor</i>
<b>9 Analysis: rich data</b>	17	7	4
	<i>Reliable</i>	<i>Not sure/ not reported</i>	<i>Unreliable</i>
<b>10 Analysis: reliable</b>	9	19	0
	<i>Convincing</i>	<i>Not sure</i>	<i>Not convincing</i>
<b>11 Analysis: convincing</b>	23	5	0
	<i>Relevant</i>	<i>Partially relevant</i>	<i>Irrelevant</i>
<b>12 Analysis: relevance to aims</b>	24	4	0
	<i>Adequate</i>	<i>Not sure</i>	<i>Inadequate</i>
<b>13 Conclusions</b>	24	3	1
	<i>Appropriate</i>	<i>Not sure/ not reported</i>	<i>Inappropriate</i>
<b>14 Ethics</b>	19	9	0
	++	+	-
<b>Overall assessment</b>	7	13	8

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**Thematic synthesis**

Eleven descriptive themes were generated from the synthesis, and gave rise to five analytical themes,[13] reflecting patient, caregiver and HCPs’ experiences of receiving and providing information about recovery. Descriptive themes are outlined in Figure 2; the five analytical themes are considered in detail below:

[Figure 2 about here]

*The right information at the right time*

In general, patients and families across studies wanted to receive information about their diagnosis and recovery prognosis from their treating medical teams.[19, 20, 23, 24, 43, 44] This usually included information about the nature of the patient’s condition, the cause, available treatments, and the prognosis or long-term prospects. However, there was some variation in what was deemed to be the ‘right’ information across conditions and individuals. Patients with SCI particularly wanted clear information about their diagnosis,[43, 44] whilst patients with stroke and TBI commonly wanted information about their recovery potential, including how long this would take and their long-term outcome.[19, 20, 23, 24] In contrast, some patients with tumours did not wish to receive prognostic information (usually in relation to a life-limiting condition):[15, 38]

*[..] when we met with the doctor, it seemed she wanted to reveal to us where we stood, and I interrupted her, and said that I really do not want to, I cannot hear that so please do not share that with me.” Caregiver, brain tumour[15]*

Overall, a source of dissatisfaction for patients and caregivers across numerous studies was a feeling that they did not receive enough information from their healthcare teams.[19, 20, 25, 26, 28, 35, 36, 38, 39, 42, 43, 46] Complaints included HCPs not being proactive in providing information,[26, 42] or not providing timely information.[19, 20, 25, 39] Patients

and caregivers described negative emotions associated with not receiving information including frustration,[19, 20, 28, 43] worry,[39] caregiver stress,[43] delay in acceptance and adjustment,[42] and decreased trust in, and poorer relationships with, their treating HCPs.[28, 42] Consistency in approach and language across different HCPs was viewed as essential, with concerns raised when different professionals provided incongruous information.[24, 28, 30]

The timing of information provision was also a key concern for patients and caregivers. In the acute phase after TBI, stroke or SCI, e.g. in the emergency room, information was often provided to families, due to the medical status of the patient. However, even where patients were medically stable, the nature of an unexpected neurological event or diagnosis meant that they or their families often felt unable to understand or retain information effectively in the early period after the event, due to their emotional state of mind, i.e. feeling overwhelmed, or in shock:[19, 20, 25, 26, 35, 38, 42]

*“In [the hospital], my wife was away for a moment when the nurses were doing their rounds, but my mom was there. And they gave her a bunch of handouts. . . And I think they may have explained a little bit about brain injury. But my mom wasn’t quite in the head-space to remember all of it at the time. [...]”* Patient with TBI[25]

Some patients and caregivers accepted these limitations and described how they wanted information to be repeated at different time-points.[25] For HCPs however, this presented a challenge: they were aware of these difficulties,[19, 20, 40, 42] but feared complaints from patients and caregivers who felt that information was not satisfactorily provided.[42] Suggested strategies to manage this situation included repetition of information at different times,[25, 26, 42] provision of written materials,[25] and providing staff contact details for patients and families to contact if they had questions at a later time.[25]



HCPs agreed that the timing of information about recovery potential needed to be right for the individual patient and caregiver, suggesting that they needed to be ‘ready’ to hear it,[12] or they risked causing anger or distress.[32] Some studies, particularly those involving stroke survivors, suggested that some patients could reject or deny information about recovery provided when they were not ready to hear it, particularly where it was perceived to be negative and challenged their hopes of returning to their previous lifestyle:[22, 32, 34, 39, 46]

*“I just thought, I’ll be all right, I’ll be all right... the people told me that you will get aphasia and that you’re going to have that for the rest of your life and I thought, yeah, I’ll be over that in a couple of weeks’ time, and never did [get over it].”* Patient with stroke[39]

Some HCPs felt that the most important time to provide information was during rehabilitation, when patients receive therapy to help them re-gain their independence, with some suggesting ‘drip-feeding’ it over time,[16, 37, 40] or providing it in the context of a formal meeting:[16]

*“In the back of your mind, you’ve got some rough plan of “I don’t think she is really going to ever get functional verbal speech” so you do your other stuff along the way to try and bring them to that point as well.”* Speech & Language Therapist[37]

In some cases, the practicalities of discharge forced therapists to discuss recovery towards the end of rehabilitation,[22, 34] particularly where a patients’ home environment was deemed unsuitable or their care needs had increased:[12, 31]

*“The patient perhaps isn’t safe to go home anymore ... and we were recommending placement, and that’s always hard to discuss with people.”* Occupational Therapist, In-patient neurology[12]

Where patients and particularly caregivers felt they didn’t receive the right information about recovery from HCPs, they sought it from other sources.[15, 19, 20, 46] Most commonly,

alternative sources included use of the internet,[15, 16, 19, 20, 46] and books and newspapers.[19, 20, 33] Human sources of information included fellow patients and their families,[16, 46] and skilled relatives or friends.[19, 20, 39, 46] Occasionally, HCPs expressed concern about the use of additional sources, worrying that information could provide false hope, particularly where the information did not pertain to the individual's specific case.[16, 33]

*Managing expectations: Treading a fine line between false hope and a devastating reality*

This theme relates only to studies in TBI, SCI, stroke and general neurology settings; none of the included studies considered rehabilitation after brain tumour.

Although HCPs felt that during rehabilitation was the best time to discuss recovery potential, this was sometimes problematic. During rehabilitation, patients were mostly engaged in therapy and motivated to work hard. Whilst HCPs endeavoured to be realistic in the information they provided, they were aware that receiving potentially 'bad news' about how much (or how little) a patient might achieve in the long-term could be distressing and demotivating. As a result, they were concerned about the impact negative information could have on patients' mood, hope and, subsequently motivation to participate in rehabilitation;[12, 16, 23, 32, 33, 40] a feeling which was echoed by some patient and caregiver participants.[39] HCPs feared that a loss of motivation could result in a negative prediction becoming a self-fulfilling prophecy:

*"I just don't want to sort of squash their hope ... they sort of give up a lot and also they don't maintain their home exercise programme."* Occupational Therapist, community rehabilitation[43]

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These fears could result in HCPs being unwilling or hesitating to discuss recovery with patients and families.[12, 23]

At the opposite end of the spectrum, HCPs also feared that a failure to manage patients’ and families’ expectations about recovery and provide realistic information could foster ‘false hope,’ and allow patients’ and families’ to maintain expectations of a return to life as they had experienced it before their neurological event.[12, 22, 28, 29, 33, 34, 42] They worried that patients, and their families, would be disappointed or distressed if their hopes for recovery were not realised.[22, 28, 33, 34] As a result, HCPs knew they must provide some realistic information to manage patients’ and carers’ expectations, but expressed that they must do so in a way that nurtured their patients’ hope and motivation; this was presented as a careful and challenging balance:[16, 22, 32-34, 37, 40]

*“You wouldn’t want to give them too high hopes, but then you also want to encourage them [...]”* Neurological physiotherapist[33]

HCPs described several strategies they used to manage the expectations of patients and their caregivers. In the acute phase, they could provide written information about the role of rehabilitation and what could be provided by their service.[16] During rehabilitation, therapists described how realistic goal-setting[12, 33, 37] and repetition of information about recovery in different forms (written, via keyworker or outreach service)[16] could help to manage expectations about what it might be possible to achieve. Where expectations were effectively managed, HCPs described benefits in enabling carers to plan for the future[12] and in facilitating discharge;[37] however where patients maintained what HCPs deemed to be unrealistic hopes for recovery, they felt this limited adjustment to disability.[22, 34]

Underlying discussions about recovery appeared to be an assumption made by patients that they would make a full recovery, and that their main route to recovery was through

rehabilitation. Where this was the case, they perceived discharge as an end to their recovery, and expressed disappointment if it occurred before their recovery expectations were met.[22, 34] In contrast, HCPs understood recovery as a long-term process, with its conclusion likely involving adaptations to a patient's previous lifestyle. In a minority of studies however, it wasn't simply the outcome of rehabilitation about which HCPs and patients were observed to have incongruous ideas, but also their understanding of the process. Whilst HCPs described that what could be achieved through therapy was mediated by spontaneous neurological recovery, only two studies described how this was conveyed to patients and families,[22, 23, 34] and this concept was rarely mentioned by patient and family participants.[22, 26, 34] Patients and families therefore, placed much emphasis on patients' motivation and effort within rehabilitation, which could result in feelings of failure if their expected level of recovery was not achieved.[19, 20] Rather than discussing the complexities of rehabilitation with patients and families, HCPs attempted to bring patients' and families' expectations and perspectives about recovery closer to their own so that they were 'on the same page'[29, 31] Strategies employed by HCPs at discharge when patients felt they had not achieved their expected recovery included negotiation of a finite number of treatment sessions or the use of objective measures to demonstrate to the patient that they were no longer making progress and thus persuade them that more therapy would not be beneficial to their recovery.[22, 34, 37]

### *Its not what you say, its how you say it*

Where HCPs feared both giving false optimism and destroying hope, patients and families described how important hope was to them.[15] Where information about recovery was provided, patients and families felt that HCPs should deliver it with compassion and

empathy,[19, 20, 26-28, 38, 39, 46] as well as positivity, allowing them to maintain hope and motivation:[19, 20, 27, 29, 36, 38, 39, 46]

*“I think they need to be more in empathy with the patient rather than just a number.”*

Patient with stroke[39]

They wanted positive messages, including a focus on the function the patient retained, rather than what they had lost:[27, 38]

*“I would prefer the initial statement to be addressing the positive aspect of the condition. e.g. ‘you are capable of doing almost all you did before the accident’.”*

Patient with SCI[27]

This presentation of ‘good news’ alongside bad news was observed,[31] and also acknowledged as a strategy by some HCPs.[40] Patients and caregivers expressed a need to feel listened to and understood, with their distress acknowledged.[25, 26, 39, 46] A private setting for information provision was important, and patients valued being able to choose whether their families were present or not.[27, 46] Sometimes, however, patients and caregivers felt HCPs were too negative in the messages they gave, resulting in distress, anxiety, fear or anger.[29, 36] Where bad experiences were recounted, they involved receiving incongruous information from different HCPs,[24, 28, 30] overhearing information,[46] not being given an opportunity to ask questions,[19, 20, 39, 46] or the use of complex medical terminology, which limited their understanding of the information.[19, 20, 30]

Patients and caregivers also described a desire for truthful and honest information about recovery,[19, 20, 24, 27-29] and HCPs felt that telling the truth was important to build relationships, gain families’ trust and maintain their own credibility:[40, 45]

*“I can take the bad news. Just don’t tell us things that are not true and think that we need to hear happy things.”* Caregiver, TBI[24]

For HCPs, a consistent approach to conveying information could help patients to process and understand what had happened to them, accept residual disability and adjust to necessary lifestyle changes.[16, 33, 37] It was also crucial to developing a trusting relationship between patients, their families and HCPs.[19, 20, 42] The use of inconsistent language between HCPs and the expression of different viewpoints could have negative effects on caregivers, including causing distress and confusion,[30] causing them to doubt the truth of what HCPs were telling them,[24, 30] triggering arguments amongst families,[24] and resulting in stress and anxiety in decision-making.[28, 30] In some studies, participants suggested having one key contact in the patient's family and one on the healthcare team, or providing written information, could aid consistency.[16, 19, 20, 24]

### *Learning how to talk about recovery and manage emotions*

Most professionals described a role in talking about recovery (with the exception of brain tumours; no included studies involved HCPs working with patients with brain tumour), and in breaking bad news, including physicians and therapists,[12, 16, 23, 29, 32, 37] although none advocated a team approach. Nurses did not take outright ownership of this role, choosing to defer to physicians or therapists,[29, 40] although some described how the round-the-clock nature of their work meant they were well-placed and available to answer patients' questions when information provided by other HCPs had had time to 'sink in'.[40]

Although therapists described a role in talking about recovery, they described lacking sufficient training or confidence, worried patients would not listen to them and felt uncomfortable answering questions outside of their expertise.[12, 16, 32] In terms of the knowledge and skills required, therapists and nurses felt communication skills were important to effectively discuss recovery with patients and families, as well as knowledge about, and

ability to predict, potential outcomes.[12, 16, 32, 33, 40] Most felt that learning to break bad news was experience-based, rather than provided via formal training,[12, 16] although some expressed an unfulfilled need for training.[12, 16, 32, 42] Where training was desired, therapists wanted it to be led by experienced colleagues, and suggested techniques such as role-play, supervision and debriefing, and reflective practice. Provision of staff support groups[12] and access to clinical guidelines were also felt to be important.[16] In terms of content, therapists wanted training to include the grieving process and breaking bad news.[16] Access to training was not discussed by physicians in the included studies, perhaps because such training is now commonly provided as part of medical education.

Where HCPs (therapists, nurses and physicians) talked about their experiences delivering information about recovery, and particularly, breaking bad news, they often described an emotional cost. Their emotional reactions ranged from awkwardness and discomfort, to worry and stress, as well as feelings of responsibility or failure:[12, 16, 22, 34, 40-42]

*“We are dealing with long term disability and we’re almost dealing with the acute stages of anger and coming to terms, [it] can be really emotionally hard for the therapist as well.”* HCP, in-patient neurorehabilitation[16]

*“I wonder if there is a sense ... almost that you have failed the patient.”*

Occupational Therapist, in-patient neurology[12]

HCPs described that these conversations became easier with experience and identified reflective practice and debriefing with team members as ways to manage their emotions.[12, 16, 40]

Patients and caregivers also described their emotional responses to discussions about recovery. This was often related to receiving ‘bad news’, and included shock (at diagnosis),[38, 42] fear,[39] anger,[39, 46] distress,[35, 39, 46] and anxiety.[35] In some

cases, the way that information about recovery or bad news was presented provoked a negative emotional response, for example, where patients felt the HCPs provided the information in a rushed or patronising manner, they could experience anger or anxiety.[39] In addition to delivering information about recovery, HCPs described a role in managing the resulting emotional reactions of patients and families.[16, 22, 32, 34, 40, 42, 45] They described how strategies such as detaching themselves from the situation and talking about their own feelings could help,[42] however some described withholding information or avoiding having conversations with patients or families to limit their emotional response.[42, 45]

#### *Talking about recovery in the context of uncertainty*

Before being able to convey information about recovery and prognosis to patients and their families, and thus meet their information needs, HCPs must feel able to make predictions about how the trajectory of an acquired neurological condition might progress for a specific individual. To do this, some described using clinical evidence or results of medical investigations, whilst others relied on their previous clinical experience; however they often felt that outcomes were still uncertain.[22, 23, 33, 34, 41] Across studies, HCPs discussed how uncertainty impacted their ability and willingness to share their predictions with patients and their families. They described how, although they might have a hunch or an instinct about how much recovery a patient was likely to achieve based on their previous experience, it was not always possible to generalise across cases, and they might encounter exceptions:[23, 33, 37]

*“I do find that most families, or the person themselves wants to know how much is this going to improve . . . how quickly that's going to happen? And I usually say*



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3       *“well, I don't know, everybody is different” and in my own mind I have probably*  
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5       *already got a gut feeling of how much change they are going to make, as in actual*  
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7       *change on testing . . . but it is not usually something that I would verbalise . . .*  
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9       *because you do get the surprises.”* Speech and Language Therapist[37]  
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13       HCPs dealt with this uncertainty in different ways. Many were afraid to convey predictions  
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15       about recovery to patients and their families for fear of being wrong, and therefore giving  
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17       false hope, causing disappointment and anger if their predictions did not come to pass; or  
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19       quashing hope unnecessarily.[22, 34, 40-42] They feared that the information provided  
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21       would be ‘used against them’ by patients and families and worried about damaging  
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23       relationships.[22, 28, 34, 42] As a result, some HCPs described how they might avoid or  
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25       delay providing information about recovery;[22, 29, 32, 34, 37, 42] which did not go  
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27       unnoticed by patients.[42, 44] Many provided vague information or made attempts to convey  
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29       the uncertainty they faced:[19, 20, 22, 23, 28, 34, 37, 42]  
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34       *“The prognosis is never certain, and when you don't know, you have to tell them you*  
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36       *don't know.”* HCP, TBI[19]  
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39       *“I just own it. I just say I'm not sure[...]*Usually I'll have a hunch, that it is going to  
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41       *go one way or the other, but I readily and openly cop to not being sure and not*  
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43       *knowing.”* Physician, Critically-ill TBI[28]  
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46       Some HCPs felt that sharing their uncertainty could instil realism in patients and families,  
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48       thus avoiding false hope, but could help patients to maintain the hope that they needed to  
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50       keep them engaged and motivated in rehabilitation.[23, 33, 37]  
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54       The extent to which patients and their families accepted the uncertainty presented to them  
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56       varied across individuals. Whilst some were able to accept it,[22, 23, 30, 34, 44] others  
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found uncertainty resulted in feelings of frustration, worry and confusion:[19, 20, 30, 36, 42, 43]

*“I don’t know what he is going to be able to do. It made me anxious I guess is probably the best way to describe it. I wanted answers and they really were not able to give me answers.”* Caregiver of patient with intracerebral haemorrhage[30]

The inability to see what the future might hold could make them feel helpless and impotent; the trajectory appeared outside of their control, and the endpoint was unclear.[23, 43]

However, some families did find hope in the uncertainty presented to them.[29, 30] The ‘not knowing’ of what may occur gave them space to hope for a positive outcome. Some described sympathy for the HCPs, who they believed were trying their best in an uncertain situation:[44]

*“Doctors never committed themselves by saying you will never walk again. However, the poor things really didn’t know what to say.”* Patient with SCI[44]

From the perspective of HCPs, some felt that patients and families generally could understand the uncertainty they were facing as professionals, whilst others accepted that uncertainty could cause frustration or distress.[37, 42]

## DISCUSSION

This study demonstrates the difficulties inherent in talking about recovery after neurological events. Although patients and caregivers desire more information about an individual’s potential for recovery, a triad of factors impact HCPs’ efforts to meet these needs, namely the uncertain trajectory of recovery, a desire to maintain patients’ hope and motivation in rehabilitation, and typically an absence of training to discuss recovery and break bad news.

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Where information is provided, patients and caregivers emphasise that it should be delivered honestly, with kindness and compassion, and most of all, positivity.

It is unsurprising that our findings indicate that patients and caregivers report unmet needs for information: This finding is common within the neurological literature.[47-50] However, our findings suggest that it may be unclear whether information provision did not occur or whether information was provided but patients and caregivers were unable to retain it, due to the shock of diagnosis, or cognitive or communication problems resulting from neurological damage, or to understand it; due to complexities in medical language. Future studies should utilise both interviews and observations of clinical practice to ascertain this. The timing of information provision is also important and past research has recognised how patients' and families' information needs may change. For example, the 'Timing it right' framework describes how caregivers of patients with stroke are initially concerned with information about whether the patient's condition is life-threatening, and following stabilisation of their medical condition, thoughts turn to whether and how much functional recovery is possible.[51] Our findings suggest that HCPs should be encouraged to consider proactively asking patients and families whether and what types of information they would prefer at different times before providing it. However, they should be aware of potential difficulties in absorbing or retaining information, particularly when provided in acute settings, and therefore consider providing written materials or contact details of HCPs where appropriate.

Our study highlights the need for consistency in the communication of recovery information to patients and families, with poorer experiences reported following receipt of different information from different HCPs. Although not unexpected in the context of an uncertain recovery trajectory, it is imperative that multidisciplinary team members are clear about their roles in discussing recovery and that the messages they provide correspond with those of their colleagues. Whilst prognostication is traditionally seen as the role of doctors and this is

appropriate particularly where disease is life-limiting disease, our study has highlighted the key role that other team members play in discussing recovery in neurorehabilitation.

Therapists contribute specific knowledge about functional recovery and their roles in therapy provision and goal-setting require them to manage expectations about what can be achieved through rehabilitation. Nurses are also well-placed to answer patients' questions about recovery, although they may defer questions to other professionals,[40] and this could potentially result in missed opportunities for communication or increase patients' anxiety. Nurses' concerns about discussing recovery with patients with neurological conditions and their families have previously been documented,[40, 52] despite an identified role in providing information to help patients and families make sense of the impact of their event to facilitate adjustment.[53] Future interventions should encourage a team-based approach to talking about recovery, and consider ways to ensure that individual conversations are appropriately shared via documentation or team meetings.

HCPs' concerns about destroying hope when trying to instil realistic expectations were evident in our study, demonstrating their awareness of the psychological impact that information about recovery, and the way it is presented, can have on patients and caregivers. Our findings highlight patients' and families' desire for empathetic and compassionate delivery of information, particularly when receiving bad news. Approaches to communicating bad news are available,[54, 55] providing recommendations, including how to prepare a patient and manage their subsequent emotions. Training incorporating these models using techniques such as role play and group discussions, have been demonstrated to be effective in increasing clinicians' confidence[56, 57] and patient satisfaction.[58] Given the roles played by therapists in talking about recovery in neurological settings identified by our review, it is perhaps surprising that only one study recognised the use of such models in their training,[32] and they described breaking bad news as a skill they were expected to have

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but learned only through experience. Future training interventions would benefit from inclusion of specific communication skills to help therapists manage conversations about recovery in ways which meet the needs of patients and their families. The role of experiential learning should be supported through the inclusion of training or shadowing opportunities specific to recovery conversations for newly qualified therapists or those new to neurological settings.

The emotional cost to HCPs involved in discussing recovery has also been highlighted in our study. Some research has explored the emotional well-being of HCPs working in neurological rehabilitation, and it has been suggested that the frequent undertaking of emotional conversations with patients (who might display behavioural symptoms and have interpersonal problems) and their families, could be linked to occupational stress and burnout.[59-61] Identified solutions to such stress for HCPs include clinical supervision, organisational and professional support and strong team relationships,[59, 62] some of which were also identified as facilitators of talking about recovery in our study. Future interventions should promote awareness of these issues and encourage practices such as debriefing and reflective practice to help HCPs manage their emotions.

**Strengths and limitations**

To our knowledge, this is the first systematic review to synthesise patients’, caregivers’ and HCPs’ views and experiences of talking about recovery in acquired neurological conditions. The synthesis of qualitative studies using rigorous methods has allowed us to understand and synthesise the perspectives of the three groups of participants in recovery conversations, which is key to developing an intervention which is acceptable to, and meets the needs of, all parties and can be effectively implemented into clinical practice.

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3 A limitation of our study is that the validity and relevance of our findings are dependent on  
4 the quality and reporting of the included studies. Appraising the quality of qualitative  
5 research is a contentious issue, both in terms of whether and how it should be completed.[63]  
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9 We employed a widely-used tool, which was designed to assess the quality of evidence to  
10 make recommendations for inclusion in public health guidance.[17] Although we did not  
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utilise quality assessment to exclude studies from our review, all the included studies were considered worthy of inclusion, as they made a valuable contribution to the synthesis.

We employed a robust search strategy with backwards and forwards citation searching to identify articles for inclusion, however the use of inconsistent terminology in this field, and in qualitative research in general, means that some eligible titles may have been missed. Additionally, the inclusion of only studies published in English may have resulted in the omission of the experiences of patients, caregivers and HCPs reported in different languages.

### Implications for future research

Our study has implications for the design of interventions to improve conversations about recovery in acquired neurological conditions. However, although research has explored views and perceptions of discussions about recovery, there is little empirical evidence about the effects of interventions. Future research and the evaluation of interventions should also consider whether talking about recovery in a structured way can impact outcomes such as patient satisfaction, mood and adjustment to disability when compared with standard care, and whether specific training for staff could improve confidence and experiences.

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**Author contributions:** LB, DJC and ST conceived of the study. LB conducted the searches. Screening was completed by LB and AF; DJC and JJ acted as consensus reviewers. LB and FW extracted data and assessed quality of the included papers. LB was responsible for the data analysis, with input from DC, AF and TC. The initial draft of the manuscript was prepared by LB then circulated among all authors for critical revision.

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### 23 **Figures:**

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26 Figure 1: PRISMA flow diagram of study selection  
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29 Figure 2: Descriptive and analytical themes  
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Figure 1: PRISMA flow diagram of study selection

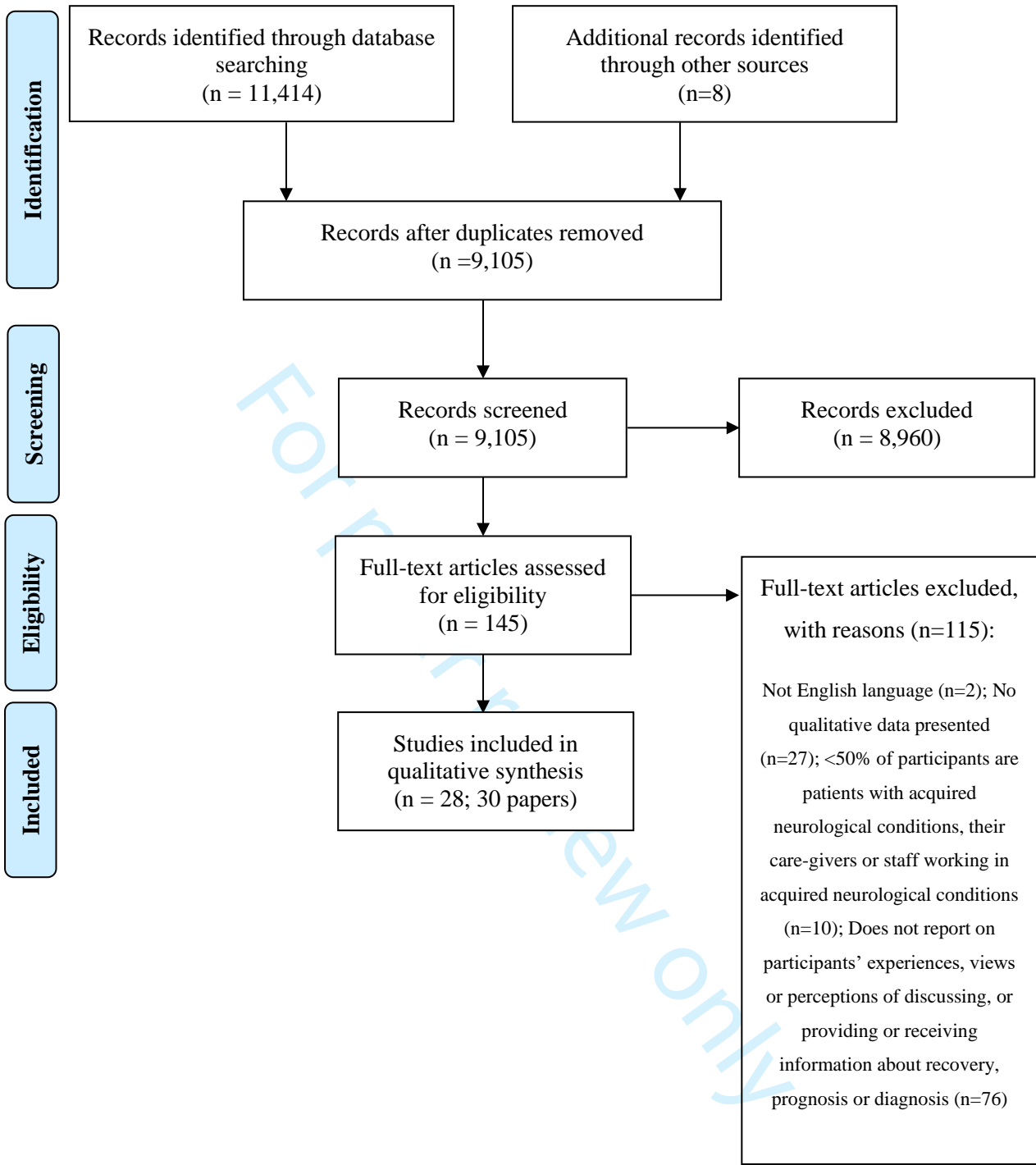
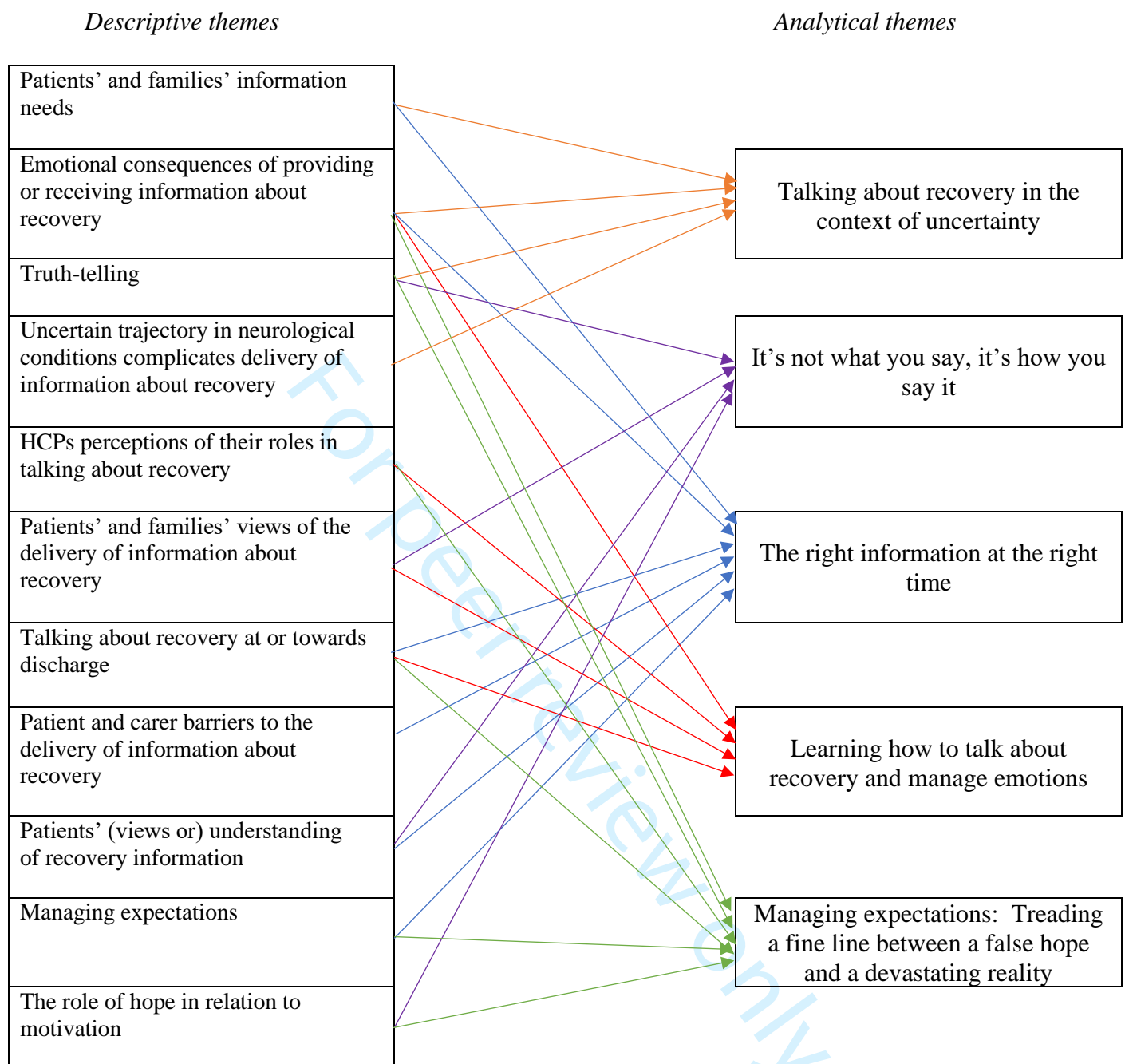


Figure 2: Descriptive and analytical themes





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**Supplementary File 1 – Example search strategy (Medline)**

- 1 (break\* adj3 news).tw.
- 2 ((difficult or bad or traumatic) adj3 news).tw.
- 3 ((communicat\* or tell\* or convey\* or disclos\* or giv\*) adj2 (diagnos\* or prognos\*)).tw.
- 4 ((inform or news) adj2 patient\*).tw.
- 5 (information provision or information exchange\* or receiving the news).tw.
- 6 (recovery adj2 (expect\* or conversation\*)).tw.
- 7 (truth-telling or truth disclosure).tw.
- 8 Truth Disclosure/
- 9 or/1-8 [breaking bad news]
- 10 (brain injur\* or head injur\* or spinal cord injur\* or spinal injur\* or multiple sclerosis or demyelinating disease\* or Parkinson\* or dementia or Alzheimer\* or vascular cognitive impair\* or lewy bod\* or huntington\* or korsako\* or motor neuron\* disease or Gehrig syndrome or amyotrophic lateral sclerosis or brain tumo?r or stroke\* or hemiplegia).tw.
- 11 (neurological adj2 (impair\* or disease\* or disorder\* or condition\*)).tw.
- 12 Brain Injuries/
- 13 Spinal Injuries/
- 14 Multiple Sclerosis/
- 15 Parkinson Disease/
- 16 Dementia/ or Dementia, Multi-Infarct/ or Dementia, Vascular/ or Frontotemporal Dementia/
- 17 Alzheimer Disease/
- 18 Amyotrophic Lateral Sclerosis/
- 19 Brain Neoplasms/
- 20 Stroke/
- 21 Hemiplegia/
- 22 or/10-21 [neurological conditions]
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- 26 24 not 25 [human only filter]
- 27 (exp Child/ or Adolescent/ or exp Infant/) not exp Adult/
- 28 26 not 27 [adult only filter]
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# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria; participants; and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Suppl file
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	7-8



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	9, Fig 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	11-17 (Tables 1-3)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	19 (Table 4)
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Thematic synthesis 20-31
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	31-32
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	34-35
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32-34
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data; role of funders for the systematic review).	36



# PRISMA 2009 Checklist

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# BMJ Open

## Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: A systematic review of qualitative literature

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**Experiences and views of receiving and delivering information about recovery in  
acquired neurological conditions: A systematic review of qualitative literature**

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Word count: 6749

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**ABSTRACT**

**Objective:** To review and synthesise qualitative literature relating to the views, perceptions and experiences of patients with acquired neurological conditions and their caregivers about the process of receiving information about recovery; as well as the views and experiences of healthcare professionals involved in delivering this information.

**Design:** Systematic review of qualitative studies

**Data sources:** MEDLINE, Embase, AMED, CINAHL, PsycINFO, Web of Science, and the Cochrane library were searched from their inception to July 2019.

**Data extraction and synthesis:** Two reviewers extracted data from the included studies and assessed quality using an established tool. Thematic synthesis was used to synthesise the findings of included studies.

**Results:** Searches yielded 9,105 titles, with 145 retained for full-text screening. Twenty-eight studies (30 papers) from eight countries were included. Inductive analysis resulted in eleven descriptive themes, from which five analytical themes were generated: The right information at the right time; Managing expectations; It’s not what you say, it’s how you say it; Learning how to talk about recovery and manage emotions; The context of uncertainty.

**Conclusions:** Our findings highlight the inherent challenges in talking about recovery in an emotional context, where breaking bad news is a key feature. Future interventions should focus on preparing staff to meet patients’ and families’ information needs, as well as ensuring they have the skills to discuss potential recovery and break bad news compassionately and share the uncertain trajectory characteristic of acquired neurological conditions. An agreed team-based approach to talking about recovery is recommended to ensure consistency and improve the experiences of patients and their families.



## ARTICLE SUMMARY

### Strengths and limitations of this study

- This is the first systematic review of findings from qualitative studies exploring discussions about recovery in the context of acquired neurological conditions, which has integrated and contrasted the experiences and perspectives of patients, their caregivers and healthcare professionals.
- Developing an understanding of the experiences and perceptions of patients, caregivers and healthcare professionals through systematic synthesis of qualitative literature using rigorous methods can inform the development of interventions to improve practice.
- Due to the diversity of language used in the field of talking about recovery and breaking bad news, it is possible that we did not identify all titles meeting our inclusion criteria; however, all efforts were made using broad search criteria and backwards and forwards citation searching.

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**BACKGROUND**

A number of acquired conditions can cause damage to the brain, spine or peripheral nervous system, including traumatic injury, stroke and haemorrhage, with over a million survivors living in the UK alone.[1] Such disorders have a sudden onset, and if survived, can result in impairments to movement, sensation, cognition, and communication, with the potential for wide-ranging effects on an individual’s daily life. For many survivors, the road to recovery is long, and rehabilitation provided by a multidisciplinary team of doctors, nurses and therapists is recommended.[2-5]

The long-term impact of these events is characterised by uncertainty,[6] and as they participate in rehabilitation, survivors often have questions about the possibility of returning to their previous lifestyles. Such questions prompt conversations about recovery, which may involve healthcare professionals (HCPs) making and conveying predictions about recovery potential and sometimes breaking bad news.[7] Bad news has been defined as “any information that produces a negative alteration to a person's expectations about their present and future” pp. 312.[8] The term is often applied in cancer and palliative care, in relation to a life-limiting prognosis. In neurological settings however, these conversations have a somewhat different focus: some recovery is often possible and discussions may relate to whether an individual will regain functions such as movement or continence, be independent in daily life and return to activities they enjoy, or participate in their vocational or social roles. Discussions may be complicated by the inherent uncertainty in neurological recovery, and the potential impact of cognitive or communication difficulties resulting from these conditions, which can require information to be presented in different formats and increased involvement from patients’ families.[7] Despite these challenges, information about recovery is important for individuals to make future plans, and potentially adjust to life with long-term disability.

As the science in predicting recovery develops,[9-11] researchers have increasingly sought to explore and understand discussions about recovery from the perspectives of those who have experienced them, namely the patients and caregivers receiving information and the HCPs who provide it (e.g.[12]). The use of qualitative methods has generated rich and detailed understanding across a variety of contexts following diagnosis of acquired neurological conditions. However, studies are often small, condition-specific and focus on a single group (patients, caregivers, or HCPs). Synthesis of qualitative literature facilitates translation of concepts across a range of studies, making their findings accessible to a wider audience and informing clinical practice and policy.[13] This review aims to bring together and synthesise findings from qualitative studies across acquired neurological conditions, including stroke, traumatic brain injury (TBI), spinal cord injury (SCI) and brain tumour, where similar issues may be encountered, to understand how conversations about recovery are viewed and experienced by patients, their families and HCPs involved in their care. Synthesis of participants' views and experiences from this review will inform our planned development of an intervention to improve conversations about recovery after stroke and would be useful for such interventions in other acquired neurological conditions.

## **METHODS**

The systematic review protocol was prospectively registered on the International Prospective Register of Systematic Reviews (PROSPERO ref: CRD42017081922) and is reported following "Enhancing Transparency in Reporting the Synthesis of Qualitative Research" (ENTREQ) guidelines (see Supplementary File 1).[14]

### **Search strategy and data management**

Electronic databases including MEDLINE, Embase, AMED, CINAHL, PsycINFO, Web of Science and the Cochrane library, were searched from time of inception to end of July 2019. A search strategy was developed with assistance from an Information Specialist (see Supplementary File 2 for an example search). Studies were eligible if they were published in English language and:

- Reported empirical qualitative research;
- >50% of participants were either adults with a diagnosis of an acquired neurological condition (stroke, TBI, SCI, brain/central nervous system tumours), their caregivers or HCPs;
- Reported experiences, views or perceptions of giving and/ or receiving information about prognosis or recovery.

There were no restrictions according to setting or time post-diagnosis. Where a paper considered the views of HCPs working across multiple neurological conditions (rather than a specific condition, e.g. in neuro-rehabilitation), these papers were considered suitable for inclusion, as it was deemed that the views of these professionals were relevant to our research question. Previous authors of systematic reviews aiming to identify papers relating to the provision of recovery information and breaking bad news have identified challenges in keyword searching, resulting from the variety of language used in this field,[15] for example, “prognostic awareness”[16] or “difficult conversations.”[17] We aimed to be as comprehensive as possible in our selection of keywords and, to ensure literature saturation, employed backwards and forwards citation searching of included articles.

Literature search results from each database were combined, and de-duplicated in EndNote. Titles and abstracts were screened for eligibility against the inclusion criteria by the lead author, with 20% independently screened by a second reviewer (AF). Full texts were

obtained for each paper deemed to meet inclusion criteria and for those where there was uncertainty. Full text review was conducted by two independent reviewers (LB and either FW or a research colleague) using a Microsoft Access database, where reasons for exclusion were recorded. Discrepancies between reviewers were discussed and referred to a third reviewer (DJC) where agreement could not be reached.

### Quality appraisal

Critical appraisal of study quality was completed using a checklist covering the core domains of quality in qualitative research (the NICE public health guidance quality appraisal checklist[18]), which assesses fourteen domains including study design and appropriateness of qualitative methods, clarity of the study aims, data collection methods including triangulation, consideration of context, the role of the researcher, analytical methods, conclusions and ethics. Included studies were graded in three categories according to whether all or most of the checklist items were fulfilled (++), some of the items were fulfilled (+), or few or none of the items were fulfilled (-).

Two independent reviewers scored each included study according to the checklist (LB and either FW or a research colleague). The primary reviewer compared both sets of scores and discussed areas of disagreement with the second reviewer. Where consensus could not be reached, a third reviewer was consulted (JJ). In this study, quality was assessed to reveal possible limitations to included studies, rather than for the purposes of exclusion. We examined the results of lower quality studies to confirm that they did not contradict the findings of higher quality studies, and that these studies did not contribute disproportionately to our conclusions. This was to ensure that the synthesis results were not biased by lower quality studies and therefore lower the risk of drawing unreliable conclusions.

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**Data extraction and synthesis**

Data were extracted from the selected papers, using a standardised form. Extracted data included study aims, sampling techniques and size, participant demographic information (age, gender, diagnosis), country, study setting, and methodology (data collection and analysis methods). Data were extracted from all included studies by two independent reviewers (LB and either FW or a research colleague) and compared to check agreement levels.

In addition, all text labelled as ‘results’ or ‘findings’, including participant quotations and author-generated analytical themes was extracted from included studies into qualitative data management software (QSR NVivo v10). Thematic synthesis[13] was selected for this study because it can be applied to review questions aiming to make recommendations for interventions,[19] and moves from initial line-by-line coding of data presented in individual studies, to subsequent development of descriptive, and then analytical, themes. Its detailed procedure addresses questions relating to transparency in qualitative synthesis by maintaining a clear link between the findings of primary studies and the review conclusions.[13]

In this study, extracted data were inductively free-coded line-by-line by the primary author. The codes generated were grouped and organised into descriptive themes to form a coding framework, which was subsequently reapplied to the included studies. The coded findings were then displayed in a framework matrix, to facilitate comparison of the views and experiences of HCPs, patients and caregivers; and to assess whether and how views and experiences might vary, depending on neurological condition and participant type. Summaries describing what was important to patients, caregivers and HCPs when talking about recovery were developed for each descriptive theme and the findings of the primary

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3 studies were then considered against the review questions to develop analytical themes. This  
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5 involved interpretation of study findings to develop an understanding of the range of issues  
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7 that are important to participants when talking about recovery and how these affect  
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9 behaviour, to make recommendations for the development of a future intervention. This  
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11 development was iterative and founded upon links between the identified descriptive themes  
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13 and their implications for how patients, caregivers and HCPs experience the provision and  
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15 receipt of information about recovery. Preliminary results were discussed amongst the  
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17 research team during the coding process, and throughout the development of themes. A draft  
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19 summary of findings was prepared by LB and circulated amongst the review team, who  
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21 suggested other potential interpretations. Following amendments, a final stage of reading  
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23 through all included studies ensured that findings were representative of the original studies.  
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## 32 **Patient and Public Involvement**

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35 Ideas for the design of the studies making up this programme of research were presented at  
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37 three groups attended by stroke survivors and caregivers (the Consumer Research Advisory  
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39 Group, and two Stroke Association-run groups in Greater Manchester). Members  
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41 commented on the importance of the research topic, and highlighted the need to understand  
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43 the views and experiences of patients and caregivers in developing an intervention. They  
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45 supported the proposals for the design and conduct of this review.  
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## 52 **RESULTS**

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55 Following removal of duplicates, the searches identified 9105 articles for title/ abstract  
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57 screening (see Figure 1). Full texts of 145 papers were retrieved for review, and 30 papers  
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reporting 28 studies were retained for inclusion. Two studies were reported in two papers each: Lefebvre & Levert[20, 21] and Wiles et al[22, 23].

[Figure 1 about here]

**Study characteristics**

The 28 included studies were conducted in eight different countries: Nine in the USA,[16, 24-31] six in the UK,[12, 17, 22, 23, 32-34] five in Australia,[35-39] three in Canada,[40-42] two in Italy,[43, 44] one each in Sweden[45] and Turkey,[46] and one in Canada and France[20, 21] (see Table 1). Included studies most frequently came from the stroke literature (n=10),[22-24, 27, 32, 33, 35, 36, 39, 45] whilst similar numbers came from TBI (n=6),[20, 21, 25, 26, 29, 30, 42] SCI (n=5),[28, 40, 43, 44, 46] and multiple neurological conditions (n=5),[12, 17, 34, 37, 41] with a minority from the brain tumour literature (n=2).[16, 38] Roughly equal numbers took place in the in-patient setting (n=10)[16, 17, 24, 25, 29-32, 40, 45] and community (n=11),[26-28, 33, 35, 36, 38, 39, 42, 44, 46], whilst a minority took place across multiple settings: in-patient and out-patient (n=2),[22, 23, 41] in-patient and community (n=3),[12, 20, 21, 43] and two included HCPs from a range of settings, including in-patient, out-patient and community[34, 37]. Of note, two studies were conducted in palliative care settings; one involved neurological conditions,[41] the other involved TBI.[30]

Five studies included data from only individuals with the condition,[28, 35, 39, 44, 46] four reported views of only caregivers,[16, 25, 31, 43] and four included perspectives of both individuals with the condition and caregivers.[26, 27, 36, 38] Seven included only HCPs, including physiotherapists,[34] occupational therapists,[12] speech and language therapists,[37] nurses,[40] doctors and nurses,[45] or a mixture of therapists,[33] or a wider mix of HCPs.[17] Three included individuals with the condition and HCPs,[22-24, 32] one



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3 included caregivers and HCPs,[29] and four included all three groups.[20, 21, 30, 41, 42]  
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5 Participant demographic data from the included studies are presented in Tables 2 and 3.  
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8 In terms of data collection, most studies used semi-structured interviews (n=17),[12, 24, 25,  
9 27, 29-31, 34, 36-39, 42-46] and three used focus groups.[20, 21, 26, 35] One used a  
10 survey,[28] and one analysed a video-taped observation.[32] Seven used mixed-methods:  
11 three employed focus groups and interviews,[17, 40, 41] one each used interviews and  
12 questionnaires,[16] observations and interviews,[22, 23] and a questionnaire and  
13 observations.[33]  
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Table 1: Characteristics of included studies

Authors	Neurological condition	Stated aim	Country	Service setting	Perspective	Sampling method	Sample size	Time after event	Data collection	Methodology/ Data analysis	Quality rating
Applebaum et al[16]	Brain tumour	To understand what informal caregivers of patients with malignant glioma understand about their loved one's prognosis, how they derived this information, what additional information they would like, and the existence of discrepancies in prognostic understanding between informal caregivers and patients with malignant glioma.	USA	Inpatient Neurology service at a Cancer Centre	Caregiver  (Patient)	Not stated	32  (32)	In-patient	Mixed - methods. Interviews and follow-up questionnaire	Inductive thematic textual analysis	-
Becker & Kaufman[24]	Stroke	To examine illness trajectories from two vantage points, that of older persons who have had a stroke and that of physicians who care for stroke patients	USA	Community hospital	Patient  Healthcare Professional	Not stated  Snowball	36  20	In-patient	Semi-structured interviews	Content analysis	+
Bond et al[25]	TBI	To discover the needs of families of patients with severe traumatic brain injury during the families' experience in a neurosurgical ICU	USA	Neurological ICU	Caregiver	Convenience	7	In-patient	Interviews	Content analysis	+
Ch'ng et al[35]	Stroke	To explore long term perspectives on coping with recovery from stroke, to inform the design of psychological interventions.	Australia	Stroke support groups	Patient	Purposive	26	Community 6 months- years	Focus groups	Thematic analysis	+
Conti et al[43]	SCI	To explore the experience of caregivers of individuals with SCI analysing the final phase of hospitalization and at 6 months from discharge, to highlight their needs during hospitalization as well as emotional experiences, reactions to difficulties resulting from being back home, and subsequent positive and negative aspects related to discharge.	Italy	SCI unit	Caregiver	Purposive	11	In-patient and community	Interviews	Phenomenology: Giorgi method	++
Dams-O'Connor et al[26]	TBI	To learn about the experiences individuals with BI have in seeking and accessing healthcare (both primary and speciality care), from the 'patient' or insider perspective, in order to better understand how providers and health systems can improve care for their patients with BI	USA	Medical centres and support groups	Patient  Caregiver	Convenience	44  1	Community 0.8-66.3 years	Focus groups	Content analysis	+
Danzl et al[27]	Stroke	To examine rural Appalachian Kentucky stroke survivors' and caregivers' experiences of receiving education from health care providers with the long-term goal of optimizing educational interactions and interventions for an underserved population	USA	Discharged patients from medical centres and rehab network (flyers/ mailshot)	Patient  Caregiver	Convenience*	13  12	Community 1-14 years	Semi-structured interviews	Content analysis	+
Dewar[40]	SCI	To explore nurses' perceptions of their role in delivering bad news in an acute spinal cord injury unit and to describe their	Canada	Acute spinal cord unit	Healthcare professional	Convenience*	22	In-patient	Focus groups, 1 interview	Grounded theory – constant comparison method	-

		experiences, difficulties, and needs as professionals.									
El Masry et al[36]	Stroke	To explore the psychosocial aspects of the experiences, concerns, and needs of caregivers of persons following stroke.	Australia	Discharged patients from neurology unit, speech therapy department and rehab hospital	Patient Caregiver	Purposive (maximum variation and theoretical sampling)	10 20	Community >3 months	Semi-structured interviews	Interpretive phenomenological analysis: Thematic analysis	++
Garrino et al[44]	SCI	To assess SCI patients' perception of care by collecting important data to improve the current hospital and rehabilitative model of care	Italy	Discharged patients from SCU	Patient	Purposive*	21	Community >3 months post-discharge	Semi-structured interviews	Narrative approach: Content analysis	-
Gofton et al[41]	Neurological conditions	To develop a conceptual understanding of the specific characteristics of palliative care in neurology and the challenges of providing palliative care in the setting of neurological illness.	Canada	Academic medical centre	Patient Caregiver Healthcare professional	Not stated Not stated Purposive	Not stated	In-patient and Out-patient palliative	Dyadic patient/caregiver interviews Focus groups	Grounded theory – constant comparison method	+
Grainger et al[32]	Stroke	To explore the practice of bad news delivery in a specific healthcare setting.	UK	Stroke rehabilitation ward	Patient Healthcare Professional	Not stated	1 1 (part of larger study)	In-patient rehabilitation	Video-recorded interaction	Ethnography: Conversation analysis	-
Hersh[37]	Neurological conditions	To discuss speech pathologists' reports about how they discharge their clients with chronic aphasia; to explore the process of weaning in order to define its nature and raise awareness of it as a common aspect of clinical practice.	Australia	Practicing SLTs	Healthcare Professional	Not stated	20	In-patient/ Out-patient and community	Semi-structured interviews	Grounded theory	-
Kirshblum et al[28]	SCI	To determine when, by whom, and in what setting persons with neurologically complete traumatic SCI want to hear of their prognosis.	USA	Medical rehabilitation facilities	Patient	Convenience	56 (45 completed qualitative component)	Community >3 months	Online survey with open and closed questions	Thematic analysis	-
Lefebvre & Levert, 2006[42]	TBI	To investigate the experiences of individuals who had sustained a TBI, their families, the physicians and health professionals involved, from the critical care episodes and subsequent rehabilitation.	Canada	Hospital rehabilitation centres; paramedical organisation and victims association	Patient Caregiver Healthcare professional	Purposive (Maximum Variation Sampling)*	8 14 36	Community mean 2.8 years	Semi-structured interviews	Thematic analysis*	+
Lefebvre & Levert, 2012[20, 21]**	TBI	To explore the needs of individuals and their loved ones throughout the continuum of care and services, from the point of view of everyone affected by the experience of a TBI. including individuals, their loved ones, and the health care professionals involved in their care.	Canada and France	Not stated Not stated Acute care, rehabilitation	Patient Caregiver Healthcare professional	Convenience	56 34 60	Community mean=4.3 years In-patient/ community	Focus groups	Thematic content analysis	+

				or social reintegration							
Lobb et al[38]	Brain tumour	To understand patient experiences of high grade glioma and to describe their information and support needs.	Australia	Tertiary centre for neurological cancers	Patients Caregivers	Purposive	19 21	Community within 1 year of diagnosis	Semi-structured interviews	Grounded theory – constant comparison method	+
Maddern & Kneebone[39]	Stroke	To explore the experience of stroke survivors when receiving bad news (RBN) from medical practitioners	Australia	Community stroke clubs	Patients	Convenience*	10	Community 2-4 years, mean=6.2 years	Semi-structured interviews	Interpretive phenomenological analysis, Thematic analysis	+
Ozyemisci-Taziran et al[46]	SCI	To investigate the process of breaking bad news from the perspective of spinal cord injury survivors.	Turkey	Discharges from in-patient rehabilitation	Patients	Not stated	14	Community 1–19 years, mean=7.5 years	Semi-structured interviews	Content analysis	-
Peel et al[17]	Neurological conditions	To explore health professionals’ lived experiences of having difficult conversations surrounding rehabilitation potential; to explore different strategies used to support these difficult conversations; and to identify how future practice could be improved.	UK	Regional neurorehabilitation unit within an acute hospital	Healthcare professional	Convenience*	15	In-patient	One focus group; 5 individual interviews	Phenomenological approach: Thematic content analysis	+
Phillips et al[33]	Stroke	To address the seemingly neglected area of BBN within stroke care, by documenting a collaborative consultation undertaken to support this skill within a multidisciplinary community stroke rehabilitation team	UK	Multidisciplinary community stroke team for early discharge	Healthcare Professional	Self-selecting*	5	Community	Case study of consultation. Self-report questionnaire, qualitative observations	Not stated	-
Quinn et al[29]	TBI	To explore key communication preferences and practices by stakeholders (surrogates and physicians) for the outcome prognostication during goals of-care discussions for critically ill TBI patients	USA	Level-1 trauma centres	Caregiver Healthcare Professional	Purposive Purposive and snowball	16 20	In-patient	Semi-structured interviews	Content analysis	+
Rejno et al[45]	Stroke	To deepen the understanding of stroke team members’ reasoning about truth telling in end-of-life care due to acute stroke with reduced consciousness	Sweden	Combined acute and rehabilitation stroke unit teams	Healthcare Professional	Convenience sample	15	In-patient	Interviews	Content analysis	++
Schutz et al[30]	TBI	To explore how family members, nurses, and physicians experience the palliative and supportive care needs of patients with severe acute brain injury receiving care in the neuroscience intensive care unit	USA	Neuro-ICU	Patient Caregiver Healthcare Professional	Purposive	15 16 31	In-patient palliative care	Semi-structured interviews	Thematic analysis	++
Sexton[12]	Neurological conditions	To answer the question, ‘What are the experiences of occupational therapists when having bad news conversations with disabled people regarding long-term neurological disability?’.	UK	Neurological OTs	Healthcare professional	Convenience	10	In-patient and community	Semi-structured interviews	Phenomenology: Thematic analysis*	++
Soundy et al[34]	Neurological conditions	To 1) explore the meanings of the different types of hope that neurological physiotherapists give to patients to consider, 2) give greater depth to the role of hope in clinical practice, 3) present the	UK	Neurological physiotherapists	Healthcare Professional	Purposive	9	In-patient, out-patient and community Clinical	Semi-structured interviews	Categorical-content analysis	++

		dilemmas of physiotherapists hope for their patient, and 4) illustrate how different disease prognoses may influence hope						specialists and educators in one UK city			
Wiles et al[22, 23] ***	Stroke	To explore the factors, associated with physiotherapists' provision of information, that may contribute to patients' high expectations of physiotherapy	UK	3 acute Trusts	Patient Healthcare Professional	Not stated	16 26	In-patient and out-patient	Longitudinal case studies – semi-structured interviews and observations	Grounded theory: Thematic analysis	++
Zahuranec et al[31]	Stroke – intracerebral haemorrhage	To examine surrogate decision maker perspectives on provider prognostic communication after intracerebral haemorrhage	USA	5 health system/ hospital/ medical centre sites	Caregiver (Patient)	Convenience*	52 (52)	In-patient: Median day from admission to interview = 35.5	Semi-structured interviews	Thematic analysis*	+

ICU=Intensive Care Unit; TBI=Traumatic Brain Injury; SCI=Spinal Cord Injury; OT=Occupational Therapist. Participants in parentheses were recruited to the study but did not participate in the qualitative element, therefore results from these participants have not been included in the analysis. \*Inferred from author's description; \*\* A second paper from the same study was also used in the analysis, which considered only the Canadian data from healthcare professionals (n=29) and caregivers (n=19); \*\*\*A second paper from the same study was also used in the analysis, which considered the process of discharge and included only the patients who had completed data at the third time=point (n=13 patients and n=21 healthcare professionals)

Table 2: Included studies, patient and carer demographics

Authors	Perspective	Sample size	Age range	Mean age	% female
Applebaum et al[16]	Caregiver	32	Not stated	Average=50	64
Becker & Kaufman[24]	Patient*	36	48-105	Not stated	64
Bond et al[25]	Caregiver	7	41-61	Not stated	71
Ch'ng et al[35]	Patient	26	22-79	60.9	54
Conti et al[43]	Caregiver	11	28-80	57.4	73
Dams-O'Connor et al[26]	Patient	44	23-72	Not stated	58
	Caregiver	1	Not stated	Not stated	Not stated
Danzl et al[27]	Patient	13	42-89	63.4	69
	Caregiver	12	38-75	55.9	58
El Masry et al[36]	Patient	10	41-50=2; 61-70=4; 71-80=3; 81-90=1	Not stated	20
	Caregiver	20	31-40=2; 41-50=2; 51-60=3; 61-70=5; 71-80=5; 81-90=3	Not stated	80
Garrino et al[44]	Patient	21	34–63 (F); 19–70 (M)	Not stated	24
Gofton et al[41]	Patient*	Not stated	Not stated	Not stated	Not stated
	Caregiver	Not stated	Not stated	Not stated	Not stated
Grainger et al[32]	Patient*	2 (part of larger study)	Not stated	Not stated	100
Kirshblum et al[28]	Patient	56 (45 completed qualitative component)	18-30=10 31-40=17 41-50=17 50+=12	Not stated	13
Lefebvre & Levert, 2006[42]	Patient*	8	18-29=5, 30-39=1, 40-49=2	28.4	25
	Caregiver	14	18–29=3; 30–39=3; 40–49=4; 50–59=10; 60+=2	46.4	64.3
Lefebvre & Levert, 2012[20, 21]*	Patient*	56	Not stated	Not stated	30
	Caregiver	34	Not stated	Not stated	59
Lobb et al[38]	Patients	19	Not stated	Not stated	37
	Caregivers	21	30-39=2; 40-49=2; 50-9=10; 60-69=6; 70+=1	Not stated	81
Maddern & Kneebone[39]	Patients	10	61-84	63.4	30
Ozyemisci-Taziran et al[46]	Patients	14	25–57	37.2 Median=35.5	7
Quinn et al[29]	Caregiver*	16	Not stated	57	56
Schutz et al[30]	Patient*	15	Not stated	46.1	33
	Caregiver	16	Not stated	Not stated	69
Wiles et al[22, 23]**	Patient*	16	41–79	66	62.5
Zahuranec et al[31]	Caregiver	52	Not stated	Median=55	60

\*A second paper from the same study was also included, with 19 caregivers, age range=28-67, mean 50.6 years; \*\*A second paper from the same study was also included, with 13 patients of the same age range/mean age, 61.5% female.

\*Study also included healthcare professionals (see Table 3)

Table 3: Included studies, Healthcare professional demographics

Authors	Perspective	Sample size	Professional roles	Age range	% female	Years of experience in practice	Years of experience with condition
Becker & Kaufman[24]	Healthcare Professional	20	Physicians	32-78	20	Not stated	Not stated
Dewar[40]	Healthcare professional	22	Nurses	22-54	Not stated	Mean=7.4	Mean=4.6
Gofton et al[41]	Healthcare professional	Not stated	Physicians 5 nurses 6 allied health professionals (SLT, OT, PT)	Not stated	Not stated	Not stated	Not stated
Grainger et al[32]	Healthcare Professional	1 (part of larger study)	OT	Not stated	100	Not stated	Not stated
Hersh[37]	Healthcare Professional	20	SLT	Not stated	97	>20 = 12; 5-20 = 14; <5 = 4	Not stated
Lefebvre & Levert, 2006[42]	Healthcare professional	36	Nurse=16.1%; PT=9.7%; OT=6.5% SLT=3.2%; Remedial teacher=3.2%; Psychologist=6.5%; Social worker=12.9%; Special educator=6.5%; Psychosocial coordinator=3.2%; Physician=29%	Not stated	Not stated	Mean=12 <5=16.1%; 6-10=19.4%; 11-15= 35.5%; 16-20=25.8%; >20 = 6.2%	Mean=8.2 <5=32.3%; 6-10=32.3%; 11-15=25.8%; 16-20=9.7%
Lefebvre & Levert, 2012[20, 21] *	Healthcare professional	60	13 psychology/ neuropsychology; 7 OT 6 social work; 5 nursing; 4 health care aid; 3 PT; 2 kinesiology; 2 SLT; 2 clinical coordination; 2 rehabilitation counselling	Not stated	68.3	Average= 15.75	1-30

Peel et al[17]	Healthcare professional	15	Physicians, nurses, OT, PT, SLT, psychologists	Not stated	80	Not stated	<1=5, >10 years=4
Phillips et al[33]	Healthcare Professional	5	2 OT, 1 PT, 1 SLT, 1 rehabilitation assistant	Not stated	100	8-10	Not stated
Quinn et al[29]	Healthcare Professional	20	Physicians	Mean age=47	35	Not stated	Median (speciality practice)=11, range=2-40
Rejno et al[45]	Healthcare Professional	15	4 physicians, 11 nurses	Mean age=48	73	Not stated	Median: 11
Schutz et al[30]	Healthcare Professional	31	Physicians Nurses	Not stated Mean age=44.7	19 80	Median=4 Median=18	Not stated
Sexton[12]	Healthcare professional	10	OT	21-30=3, 31-40=5, 41-50=2	90	11 (range=2-27)	6.9 (range=1-13)
Soundy et al[34]	Healthcare Professional	9	PT	Mean age=43.2	100	Not stated	4-17 (median=10)
Wiles et al[22, 23]**	Healthcare Professional	26	PT	Not stated	Not stated	Not stated	Not stated

SLT=Speech and Language Therapist; OT=Occupational Therapist; PT=Physiotherapist; \*A second paper from the same study was also included, with 29 healthcare professionals of the same professions, average experience in rehabilitation=13 years, no other demographics available. \*\*A second paper from the same study was also included, with 21 PT, no other demographics available.



## Quality assessment

Table 4 details the methodological quality of included studies. Most (n=20) were scored + or ++, suggesting that all/ most or some of the criteria were met, and where there was insufficient description the conclusions would be unlikely to change. Of the eight studies deemed to be of lower quality, four lacked richness of the data presented.[27, 28, 44, 46] In four, the context from which the data were drawn was unclear,[33, 37, 40, 41] and in three, the analysis did not appear sufficiently rigorous.[33, 40, 46] In three studies, research methodology was not adequately justified,[32] data collection methods were not clearly described,[32] methods were felt to be unreliable,[40] or the links between the findings and conclusions were unclear.[28]

Table 4: Methodological quality of included studies

	<i>Appropriate</i>	<i>Not sure</i>	<i>Inappropriate</i>
<b>1 Theoretical approach: appropriateness</b>	28	0	0
	<i>Clear</i>	<i>Mixed</i>	<i>Unclear</i>
<b>2 Theoretical approach: clarity</b>	24	4	0
	<i>Defensible</i>	<i>Not sure</i>	<i>Indefensible</i>
<b>3 Research design/ methodology</b>	10	17	1
	<i>Appropriately</i>	<i>Not sure/ Inadequately reported</i>	<i>Inappropriately</i>
<b>4 Data collection</b>	14	13	1
	<i>Clearly described</i>	<i>Not described</i>	<i>Unclear</i>
<b>5 Trustworthiness: role of the researcher</b>	4	24	0
	<i>Clear</i>	<i>Not sure</i>	<i>Unclear</i>
<b>6 Trustworthiness: context</b>	15	9	4
	<i>Reliable</i>	<i>Not sure</i>	<i>Unreliable</i>
<b>7 Trustworthiness: reliable methods</b>	7	20	1
	<i>Rigorous</i>	<i>Not sure/ not reported</i>	<i>Not rigorous</i>
<b>8 Analysis: rigorous</b>	16	9	3
	<i>Rich</i>	<i>Not sure/ not reported</i>	<i>Poor</i>
<b>9 Analysis: rich data</b>	17	7	4
	<i>Reliable</i>	<i>Not sure/ not reported</i>	<i>Unreliable</i>
<b>10 Analysis: reliable</b>	9	19	0
	<i>Convincing</i>	<i>Not sure</i>	<i>Not convincing</i>
<b>11 Analysis: convincing</b>	23	5	0
	<i>Relevant</i>	<i>Partially relevant</i>	<i>Irrelevant</i>
<b>12 Analysis: relevance to aims</b>	24	4	0
	<i>Adequate</i>	<i>Not sure</i>	<i>Inadequate</i>
<b>13 Conclusions</b>	24	3	1
	<i>Appropriate</i>	<i>Not sure/ not reported</i>	<i>Inappropriate</i>
<b>14 Ethics</b>	19	9	0
	++	+	-
<b>Overall assessment</b>	7	13	8

## Thematic synthesis

Eleven descriptive themes were generated from the synthesis, and gave rise to five analytical themes,[13] reflecting patient, caregiver and HCPs' experiences of receiving and providing information about recovery. Descriptive themes are outlined in Figure 2; the five analytical themes are considered in detail below:

[Figure 2 about here]

### *The right information at the right time*

In general, patients and families across studies wanted to receive information about their diagnosis and recovery prognosis from their treating medical teams.[20, 21, 24, 25, 43, 44] This usually included information about the nature of the patient's condition, the cause, available treatments, and the prognosis or long-term prospects. However, there was some variation in what was deemed to be the 'right' information across conditions and individuals. Patients with SCI particularly wanted clear information about their diagnosis,[43, 44] whilst patients with stroke and TBI commonly wanted information about their recovery potential, including how long this would take and their long-term outcome.[20, 21, 24, 25] In contrast, some patients with tumours did not wish to receive prognostic information (usually in relation to a life-limiting condition):[16, 38]

*[...] when we met with the doctor, it seemed she wanted to reveal to us where we stood, and I interrupted her, and said that I really do not want to, I cannot hear that so please do not share that with me."* Caregiver, brain tumour[16]

Overall, a source of dissatisfaction for patients and caregivers across numerous studies was a feeling that they did not receive enough information from their healthcare teams.[20, 21, 26, 27, 29, 35, 36, 38, 39, 42, 43, 46] Complaints included HCPs not being proactive in providing information,[27, 42] or not providing timely information.[20, 21, 26, 39] Patients

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and caregivers described negative emotions associated with not receiving information including frustration,[20, 21, 29, 43] worry,[39] caregiver stress,[43] delay in acceptance and adjustment,[42] and decreased trust in, and poorer relationships with, their treating HCPs.[29, 42] Consistency in approach and language across different HCPs was viewed as essential, with concerns raised when different professionals provided incongruous information.[25, 29, 31]

The timing of information provision was also a key concern for patients and caregivers. In the acute phase after TBI, stroke or SCI, e.g. in the emergency room, information was often provided to families, due to the medical status of the patient. However, even where patients were medically stable, the nature of an unexpected neurological event or diagnosis meant that they or their families often felt unable to understand or retain information effectively in the early period after the event, due to their emotional state of mind, i.e. feeling overwhelmed, or in shock:[20, 21, 26, 27, 35, 38, 42]

*“In [the hospital], my wife was away for a moment when the nurses were doing their rounds, but my mom was there. And they gave her a bunch of handouts. . . And I think they may have explained a little bit about brain injury. But my mom wasn’t quite in the head-space to remember all of it at the time. [...]”* Patient with TBI[26]

Some patients and caregivers accepted these limitations and described how they wanted information to be repeated at different time-points.[26] For HCPs however, this presented a challenge: they were aware of these difficulties,[20, 21, 40, 42] but feared complaints from patients and caregivers who felt that information was not satisfactorily provided.[42] Suggested strategies to manage this situation included repetition of information at different times,[26, 27, 42] provision of written materials,[26] and providing staff contact details for patients and families to contact if they had questions at a later time.[26]

HCPs agreed that the timing of information about recovery potential needed to be right for the individual patient and caregiver, suggesting that they needed to be ‘ready’ to hear it,[12] or they risked causing anger or distress.[33] Some studies, particularly those involving stroke survivors, suggested that some patients could reject or deny information about recovery provided when they were not ready to hear it, particularly where it was perceived to be negative and challenged their hopes of returning to their previous lifestyle:[22, 23, 33, 39, 46]

*“I just thought, I’ll be all right, I’ll be all right... the people told me that you will get aphasia and that you’re going to have that for the rest of your life and I thought, yeah, I’ll be over that in a couple of weeks’ time, and never did [get over it].”* Patient with stroke[39]

Some HCPs felt that the most important time to provide information was during rehabilitation (although of note, no studies included the rehabilitation of patients with brain tumours), when patients receive therapy to help them re-gain their independence, with some suggesting ‘drip-feeding’ it over time,[17, 37, 40] or providing it in the context of a formal meeting:[17]

*“In the back of your mind, you’ve got some rough plan of “I don’t think she is really going to ever get functional verbal speech” so you do your other stuff along the way to try and bring them to that point as well.”* Speech & Language Therapist[37]

In some cases, the practicalities of discharge forced therapists to discuss recovery towards the end of rehabilitation,[22, 23] particularly where a patients’ home environment was deemed unsuitable or their care needs had increased:[12, 32]

*“The patient perhaps isn’t safe to go home anymore ... and we were recommending placement, and that’s always hard to discuss with people.”* Occupational Therapist, In-patient neurology[12]

Where patients and particularly caregivers felt they didn’t receive the right information about recovery from HCPs, they sought it from other sources.[16, 20, 21, 46] Most commonly,

alternative sources included use of the internet,[16, 17, 20, 21, 46] and books and newspapers.[20, 21, 34] Human sources of information included fellow patients and their families,[17, 46] and skilled relatives or friends.[20, 21, 39, 46] Occasionally, HCPs expressed concern about the use of additional sources, worrying that information could provide false hope, particularly where the information did not pertain to the individual's specific case.[17, 34]

*Managing expectations: Treading a fine line between false hope and a devastating reality*

This theme relates only to studies in TBI, SCI, stroke and general neurology settings; none of the included studies considered rehabilitation after brain tumour.

Although HCPs felt that during rehabilitation was the best time to discuss recovery potential, this was sometimes problematic. During rehabilitation, patients were mostly engaged in therapy and motivated to work hard. Whilst HCPs endeavoured to be realistic in the information they provided, they were aware that receiving potentially 'bad news' about how much (or how little) a patient might achieve in the long-term could be distressing and demotivating. As a result, they were concerned about the impact negative information could have on patients' mood, hope and, subsequently motivation to participate in rehabilitation;[12, 17, 24, 33, 34, 40] a feeling which was echoed by some patient and caregiver participants.[39] HCPs feared that a loss of motivation could result in a negative prediction becoming a self-fulfilling prophecy:

*"I just don't want to sort of squash their hope ... they sort of give up a lot and also they don't maintain their home exercise programme."* Occupational Therapist, community rehabilitation[43]

These fears could result in HCPs being unwilling or hesitating to discuss recovery with patients and families.[12, 24]

At the opposite end of the spectrum, HCPs also feared that a failure to manage patients' and families' expectations about recovery and provide realistic information could foster 'false hope,' and allow patients' and families' to maintain expectations of a return to life as they had experienced it before their neurological event.[12, 22, 23, 29, 30, 34, 42] They worried that patients, and their families, would be disappointed or distressed if their hopes for recovery were not realised.[22, 23, 29, 34] As a result, HCPs knew they must provide some realistic information to manage patients' and carers' expectations, but expressed that they must do so in a way that nurtured their patients' hope and motivation; this was presented as a careful and challenging balance:[17, 22, 23, 33, 34, 37, 40]

*"You wouldn't want to give them too high hopes, but then you also want to encourage them [...]"* Neurological physiotherapist[34]

HCPs described several strategies they used to manage the expectations of patients and their caregivers. In the acute phase, they could provide written information about the role of rehabilitation and what could be provided by their service.[17] During rehabilitation, therapists described how realistic goal-setting[12, 34, 37] and repetition of information about recovery in different forms (written, via keyworker or outreach service)[17] could help to manage expectations about what it might be possible to achieve. Where expectations were effectively managed, HCPs described benefits in enabling carers to plan for the future[12] and in facilitating discharge;[37] however where patients maintained what HCPs deemed to be unrealistic hopes for recovery, they felt this limited adjustment to disability.[22, 23]

Underlying discussions about recovery appeared to be an assumption made by patients that they would make a full recovery, and that their main route to recovery was through

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rehabilitation. Where this was the case, they perceived discharge as an end to their recovery, and expressed disappointment if it occurred before their recovery expectations were met.[22, 23] In contrast, HCPs understood recovery as a long-term process, with its conclusion likely involving adaptations to a patient’s previous lifestyle. In a minority of studies however, it wasn’t simply the outcome of rehabilitation about which HCPs and patients were observed to have incongruous ideas, but also their understanding of the process. Whilst HCPs described that what could be achieved through therapy was mediated by spontaneous neurological recovery, only two studies described how this was conveyed to patients and families,[22-24] and this concept was rarely mentioned by patient and family participants.[22, 23, 27] Patients and families therefore, placed much emphasis on patients’ motivation and effort within rehabilitation, which could result in feelings of failure if their expected level of recovery was not achieved.[20, 21] Rather than discussing the complexities of rehabilitation with patients and families, HCPs attempted to bring patients’ and families’ expectations and perspectives about recovery closer to their own so that they were ‘on the same page’[30, 32] Strategies employed by HCPs at discharge when patients felt they had not achieved their expected recovery included negotiation of a finite number of treatment sessions or the use of objective measures to demonstrate to the patient that they were no longer making progress and thus persuade them that more therapy would not be beneficial to their recovery.[22, 23, 37]

*Its not what you say, its how you say it*

Where HCPs feared both giving false optimism and destroying hope, patients and families described how important hope was to them.[16] Where information about recovery was provided, patients and families felt that HCPs should deliver it with compassion and



empathy,[20, 21, 27-29, 38, 39, 46] as well as positivity, allowing them to maintain hope and motivation:[20, 21, 28, 30, 36, 38, 39, 46]

*"I think they need to be more in empathy with the patient rather than just a number."*

Patient with stroke[39]

They wanted positive messages, including a focus on the function the patient retained, rather than what they had lost:[28, 38]

*"I would prefer the initial statement to be addressing the positive aspect of the condition. e.g. 'you are capable of doing almost all you did before the accident'."*

Patient with SCI[28]

This presentation of 'good news' alongside bad news was observed,[32] and also acknowledged as a strategy by some HCPs.[40] Patients and caregivers expressed a need to feel listened to and understood, with their distress acknowledged.[26, 27, 39, 46] A private setting for information provision was important, and patients valued being able to choose whether their families were present or not.[28, 46] Sometimes, however, patients and caregivers felt HCPs were too negative in the messages they gave, resulting in distress, anxiety, fear or anger.[30, 36] Where bad experiences were recounted, they involved receiving incongruous information from different HCPs,[25, 29, 31] overhearing information,[46] not being given an opportunity to ask questions,[20, 21, 39, 46] or the use of complex medical terminology, which limited their understanding of the information.[20, 21, 31]

Patients and caregivers also described a desire for truthful and honest information about recovery,[20, 21, 25, 28-30] and HCPs felt that telling the truth was important to build relationships, gain families' trust and maintain their own credibility:[40, 45]

*"I can take the bad news. Just don't tell us things that are not true and think that we need to hear happy things."* Caregiver, TBI[25]

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For HCPs, a consistent approach to conveying information could help patients to process and understand what had happened to them, accept residual disability and adjust to necessary lifestyle changes.[17, 34, 37] It was also crucial to developing a trusting relationship between patients, their families and HCPs.[20, 21, 42] The use of inconsistent language between HCPs and the expression of different viewpoints could have negative effects on caregivers, including causing distress and confusion,[31] causing them to doubt the truth of what HCPs were telling them,[25, 31] triggering arguments amongst families,[25] and resulting in stress and anxiety in decision-making.[29, 31] In some studies, participants suggested having one key contact in the patient’s family and one on the healthcare team, or providing written information, could aid consistency.[17, 20, 21, 25]

*Learning how to talk about recovery and manage emotions*

Most professionals described a role in talking about recovery (with the exception of brain tumours; no included studies involved HCPs working with patients with brain tumour), and in breaking bad news, including physicians and therapists,[12, 17, 24, 30, 33, 37] although none advocated a team approach. Nurses did not take outright ownership of this role, choosing to defer to physicians or therapists,[30, 40] although some described how the round-the-clock nature of their work meant they were well-placed and available to answer patients’ questions when information provided by other HCPs had had time to ‘sink in’.[40]

Although therapists described a role in talking about recovery, they described lacking sufficient training or confidence, worried patients would not listen to them and felt uncomfortable answering questions outside of their expertise.[12, 17, 33] In terms of the knowledge and skills required, therapists and nurses felt communication skills were important to effectively discuss recovery with patients and families, as well as knowledge about, and

ability to predict, potential outcomes.[12, 17, 33, 34, 40] Most felt that learning to break bad news was experience-based, rather than provided via formal training,[12, 17] although some expressed an unfulfilled need for training.[12, 17, 33, 42] Where training was desired, therapists wanted it to be led by experienced colleagues, and suggested techniques such as role-play, supervision and debriefing, and reflective practice. Provision of staff support groups[12] and access to clinical guidelines were also felt to be important.[17] In terms of content, therapists wanted training to include the grieving process and breaking bad news.[17] Access to training was not discussed by physicians in the included studies, perhaps because such training is now commonly provided as part of medical education.

Where HCPs (therapists, nurses and physicians) talked about their experiences delivering information about recovery, and particularly, breaking bad news, they often described an emotional cost. Their emotional reactions ranged from awkwardness and discomfort, to worry and stress, as well as feelings of responsibility or failure:[12, 17, 22, 23, 40-42]

*“We are dealing with long term disability and we’re almost dealing with the acute stages of anger and coming to terms, [it] can be really emotionally hard for the therapist as well.”* HCP, in-patient neurorehabilitation[17]

*“I wonder if there is a sense ... almost that you have failed the patient.”*

Occupational Therapist, in-patient neurology[12]

HCPs described that these conversations became easier with experience and identified reflective practice and debriefing with team members as ways to manage their emotions.[12, 17, 40]

Patients and caregivers also described their emotional responses to discussions about recovery. This was often related to receiving ‘bad news’, and included shock (at diagnosis),[38, 42] fear,[39] anger,[39, 46] distress,[35, 39, 46] and anxiety.[35] In some

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cases, the way that information about recovery or bad news was presented provoked a negative emotional response, for example, where patients felt the HCPs provided the information in a rushed or patronising manner, they could experience anger or anxiety.[39] In addition to delivering information about recovery, HCPs described a role in managing the resulting emotional reactions of patients and families.[17, 22, 23, 33, 40, 42, 45] They described how strategies such as detaching themselves from the situation and talking about their own feelings could help,[42] however some described withholding information or avoiding having conversations with patients or families to limit their emotional response.[42, 45]

*Talking about recovery in the context of uncertainty*

Before being able to convey information about recovery and prognosis to patients and their families, and thus meet their information needs, HCPs must feel able to make predictions about how the trajectory of an acquired neurological condition might progress for a specific individual. To do this, some described using clinical evidence or results of medical investigations, whilst others relied on their previous clinical experience; however they often felt that outcomes were still uncertain.[22-24, 34, 41] Across studies, HCPs discussed how uncertainty impacted their ability and willingness to share their predictions with patients and their families. They described how, although they might have a hunch or an instinct about how much recovery a patient was likely to achieve based on their previous experience, it was not always possible to generalise across cases, and they might encounter exceptions:[24, 34, 37]

*“I do find that most families, or the person themselves wants to know how much is this going to improve . . . how quickly that's going to happen? And I usually say*

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3       *“well, I don't know, everybody is different” and in my own mind I have probably*  
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5       *already got a gut feeling of how much change they are going to make, as in actual*  
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7       *change on testing . . . but it is not usually something that I would verbalise . . .*  
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9       *because you do get the surprises.”* Speech and Language Therapist[37]  
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13 HCPs dealt with this uncertainty in different ways. Many were afraid to convey predictions  
14 about recovery to patients and their families for fear of being wrong, and therefore giving  
15 false hope, causing disappointment and anger if their predictions did not come to pass; or  
16 quashing hope unnecessarily.[22, 23, 40-42] They feared that the information provided  
17 would be ‘used against them’ by patients and families and worried about damaging  
18 relationships.[22, 23, 29, 42] As a result, some HCPs described how they might avoid or  
19 delay providing information about recovery;[22, 23, 30, 33, 37, 42] which did not go  
20 unnoticed by patients.[42, 44] Many provided vague information or made attempts to convey  
21 the uncertainty they faced:[20-24, 29, 37, 42]  
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34       *“The prognosis is never certain, and when you don't know, you have to tell them you*  
35  
36       *don't know.”* HCP, TBI[20]  
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39       *“I just own it. I just say I'm not sure[...]* Usually I'll have a hunch, that it is going to  
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41       *go one way or the other, but I readily and openly cop to not being sure and not*  
42  
43       *knowing.”* Physician, Critically-ill TBI[29]  
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46 Some HCPs felt that sharing their uncertainty could instil realism in patients and families,  
47 thus avoiding false hope, but could help patients to maintain the hope that they needed to  
48 keep them engaged and motivated in rehabilitation.[24, 34, 37]  
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52 The extent to which patients and their families accepted the uncertainty presented to them  
53 varied across individuals. Whilst some were able to accept it,[22-24, 31, 44] others found  
54 uncertainty resulted in feelings of frustration, worry and confusion:[20, 21, 31, 36, 42, 43]  
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*“I don’t know what he is going to be able to do. It made me anxious I guess is probably the best way to describe it. I wanted answers and they really were not able to give me answers.”* Caregiver of patient with intracerebral haemorrhage[31]

The inability to see what the future might hold could make them feel helpless and impotent; the trajectory appeared outside of their control, and the endpoint was unclear.[24, 43]

However, some families did find hope in the uncertainty presented to them.[30, 31] The ‘not knowing’ of what may occur gave them space to hope for a positive outcome. Some described sympathy for the HCPs, who they believed were trying their best in an uncertain situation:[44]

*“Doctors never committed themselves by saying you will never walk again. However, the poor things really didn’t know what to say.”* Patient with SCI[44]

From the perspective of HCPs, some felt that patients and families generally could understand the uncertainty they were facing as professionals, whilst others accepted that uncertainty could cause frustration or distress.[37, 42]

**DISCUSSION**

This study demonstrates the difficulties inherent in talking about recovery after neurological events. Although patients and caregivers desire more information about an individual’s potential for recovery, a triad of factors impact HCPs’ efforts to meet these needs, namely the uncertain trajectory of recovery, a desire to maintain patients’ hope and motivation in rehabilitation, and typically an absence of training to discuss recovery and break bad news. Where information is provided, patients and caregivers emphasise that it should be delivered honestly, with kindness and compassion, and most of all, positivity.

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3 It is unsurprising that our findings indicate that patients and caregivers report unmet needs for  
4 information: This finding is common within the neurological literature.[47-50] However,  
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6 our findings suggest that it may be unclear whether information provision did not occur or  
7  
8 whether information was provided but patients and caregivers were unable to retain it, due to  
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10 the shock of diagnosis, or cognitive or communication problems resulting from neurological  
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12 damage, or to understand it; due to complexities in medical language. Future studies should  
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14 utilise both interviews and observations of clinical practice to ascertain this. The timing of  
15  
16 information provision is also important and past research has recognised how patients' and  
17  
18 families' information needs may change. For example, the 'Timing it right' framework  
19  
20 describes how caregivers of patients with stroke are initially concerned with information  
21  
22 about whether the patient's condition is life-threatening, and following stabilisation of their  
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24 medical condition, thoughts turn to whether and how much functional recovery is  
25  
26 possible.[51] Our findings suggest that HCPs should be encouraged to consider proactively  
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28 asking patients and families whether and what types of information they would prefer at  
29  
30 different times before providing it. However, they should be aware of potential difficulties in  
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32 absorbing or retaining information, particularly when provided in acute settings, and  
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34 therefore consider providing written materials or contact details of HCPs where appropriate.  
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37 Our study highlights the need for consistency in the communication of recovery information  
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39 to patients and families, with poorer experiences reported following receipt of different  
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41 information from different HCPs. Although not unexpected in the context of an uncertain  
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43 recovery trajectory, it is imperative that multidisciplinary team members are clear about their  
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45 roles in discussing recovery and that the messages they provide correspond with those of their  
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47 colleagues. Whilst prognostication is traditionally seen as the role of doctors and this is  
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49 appropriate particularly where disease is life-limiting disease, our study has highlighted the  
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51 key role that other team members play in discussing recovery in neurorehabilitation.  
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Therapists contribute specific knowledge about functional recovery and their roles in therapy provision and goal-setting require them to manage expectations about what can be achieved through rehabilitation. Nurses are also well-placed to answer patients’ questions about recovery, although they may defer questions to other professionals,[40] and this could potentially result in missed opportunities for communication or increase patients’ anxiety. Nurses’ concerns about discussing recovery with patients with neurological conditions and their families have previously been documented,[40, 52] despite an identified role in providing information to help patients and families make sense of the impact of their event to facilitate adjustment.[53] Future interventions should encourage a team-based approach to talking about recovery, and consider ways to ensure that individual conversations are appropriately shared via documentation or team meetings.

HCPs’ concerns about destroying hope when trying to instil realistic expectations were evident in our study, demonstrating their awareness of the psychological impact that information about recovery, and the way it is presented, can have on patients and caregivers. Our findings highlight patients’ and families’ desire for empathetic and compassionate delivery of information, particularly when receiving bad news. Approaches to communicating bad news are available,[54, 55] providing recommendations, including how to prepare a patient and manage their subsequent emotions. Training incorporating these models using techniques such as role play and group discussions, have been demonstrated to be effective in increasing clinicians’ confidence[56, 57] and patient satisfaction.[58] Given the roles played by therapists in talking about recovery in neurological settings identified by our review, it is perhaps surprising that only one study recognised the use of such models in their training,[33] and they described breaking bad news as a skill they were expected to have but learned only through experience. Future training interventions would benefit from inclusion of specific communication skills to help therapists manage conversations about



recovery in ways which meet the needs of patients and their families. The role of experiential learning should be supported through the inclusion of training or shadowing opportunities specific to recovery conversations for newly qualified therapists or those new to neurological settings.

The emotional cost to HCPs involved in discussing recovery has also been highlighted in our study. Some research has explored the emotional well-being of HCPs working in neurological rehabilitation, and it has been suggested that the frequent undertaking of emotional conversations with patients (who might display behavioural symptoms and have interpersonal problems) and their families, could be linked to occupational stress and burnout.[59-61] Identified solutions to such stress for HCPs include clinical supervision, organisational and professional support and strong team relationships,[59, 62] some of which were also identified as facilitators of talking about recovery in our study. Future interventions should promote awareness of these issues and encourage practices such as debriefing and reflective practice to help HCPs manage their emotions.

### **Strengths and limitations**

To our knowledge, this is the first systematic review to synthesise patients', caregivers' and HCPs' views and experiences of talking about recovery in acquired neurological conditions. The synthesis of qualitative studies using rigorous methods has allowed us to understand and synthesise the perspectives of the three groups of participants in recovery conversations, which is key to developing an intervention which is acceptable to, and meets the needs of, all parties and can be effectively implemented into clinical practice.

A limitation of our study is that the validity and relevance of our findings are dependent on the quality and reporting of the included studies. Appraising the quality of qualitative

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research is a contentious issue, both in terms of whether and how it should be completed.[63]

We employed a widely-used tool, which was designed to assess the quality of evidence to make recommendations for inclusion in public health guidance.[18] Although we did not utilise quality assessment to exclude studies from our review, all the included studies were considered worthy of inclusion, as they made a valuable contribution to the synthesis.

We employed a robust search strategy with backwards and forwards citation searching to identify articles for inclusion, however the use of inconsistent terminology in this field, and in qualitative research in general, means that some eligible titles may have been missed.

Additionally, the inclusion of only studies published in English may have resulted in the omission of the experiences of patients, caregivers and HCPs reported in different languages.

**Implications for future research**

Our study has implications for the design of interventions to improve conversations about recovery in acquired neurological conditions. However, although research has explored views and perceptions of discussions about recovery, there is little empirical evidence about the effects of interventions. Future research and the evaluation of interventions should also consider whether talking about recovery in a structured way can impact outcomes such as patient satisfaction, mood and adjustment to disability when compared with standard care, and whether specific training for staff could improve confidence and experiences.

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8  
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10  
11 searches. Screening was completed by LB and AF; DJC and JJ acted as consensus reviewers.  
12  
13 LB and FW extracted data and assessed quality of the included papers. LB was responsible  
14  
15 for the data analysis, with input from DJC, AF and TFC. The initial draft of the manuscript  
16  
17 was prepared by LB then circulated among all authors for critical revision.  
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20  
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28

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30 **Data availability:** The data extracted from papers included in the systematic are already  
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32 published and in the public domain.  
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**Figures:**

Figure 1: PRISMA flow diagram of study selection

Figure 2: Descriptive and analytical themes

Figure 1: PRISMA flow diagram of study selection

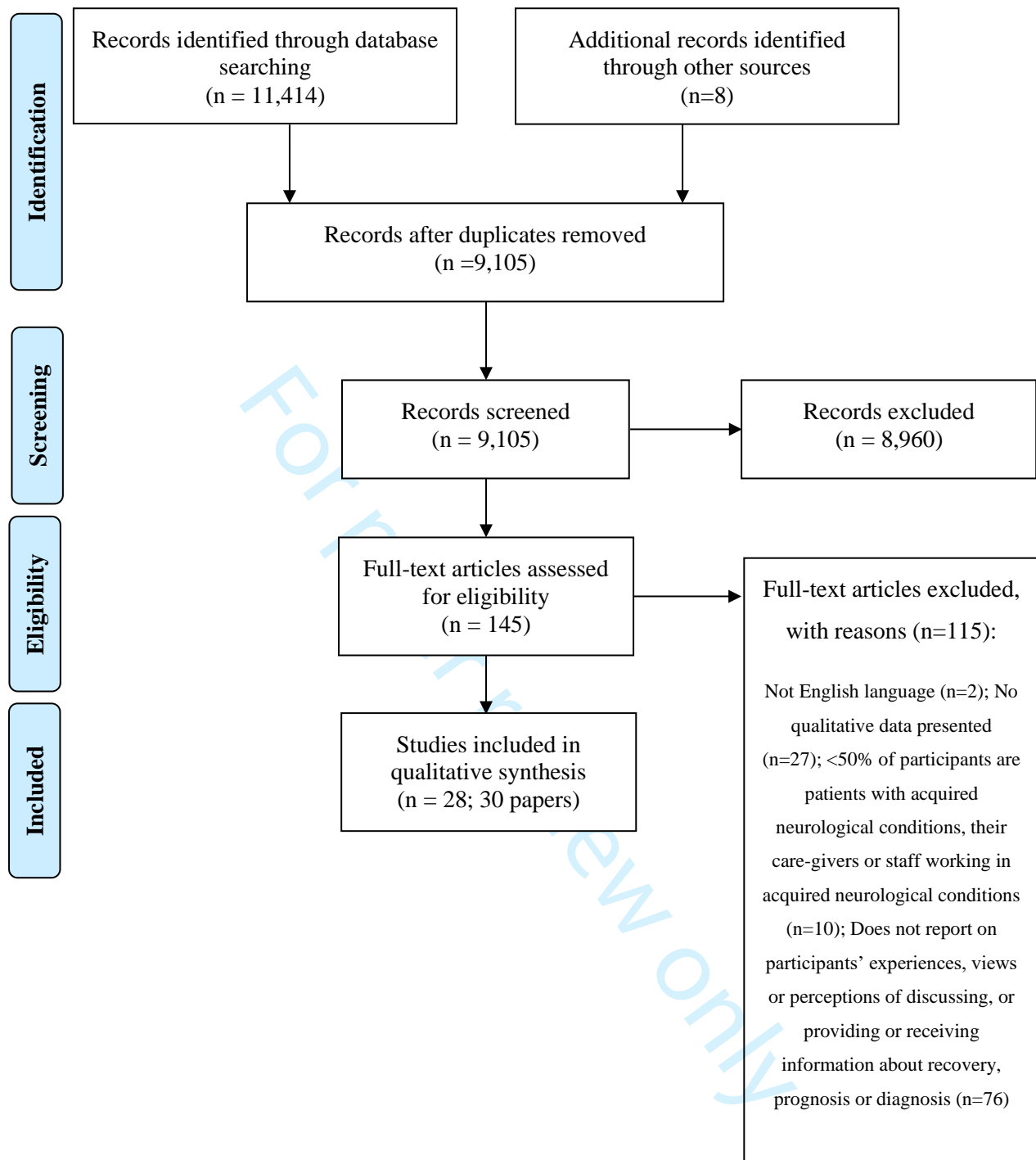
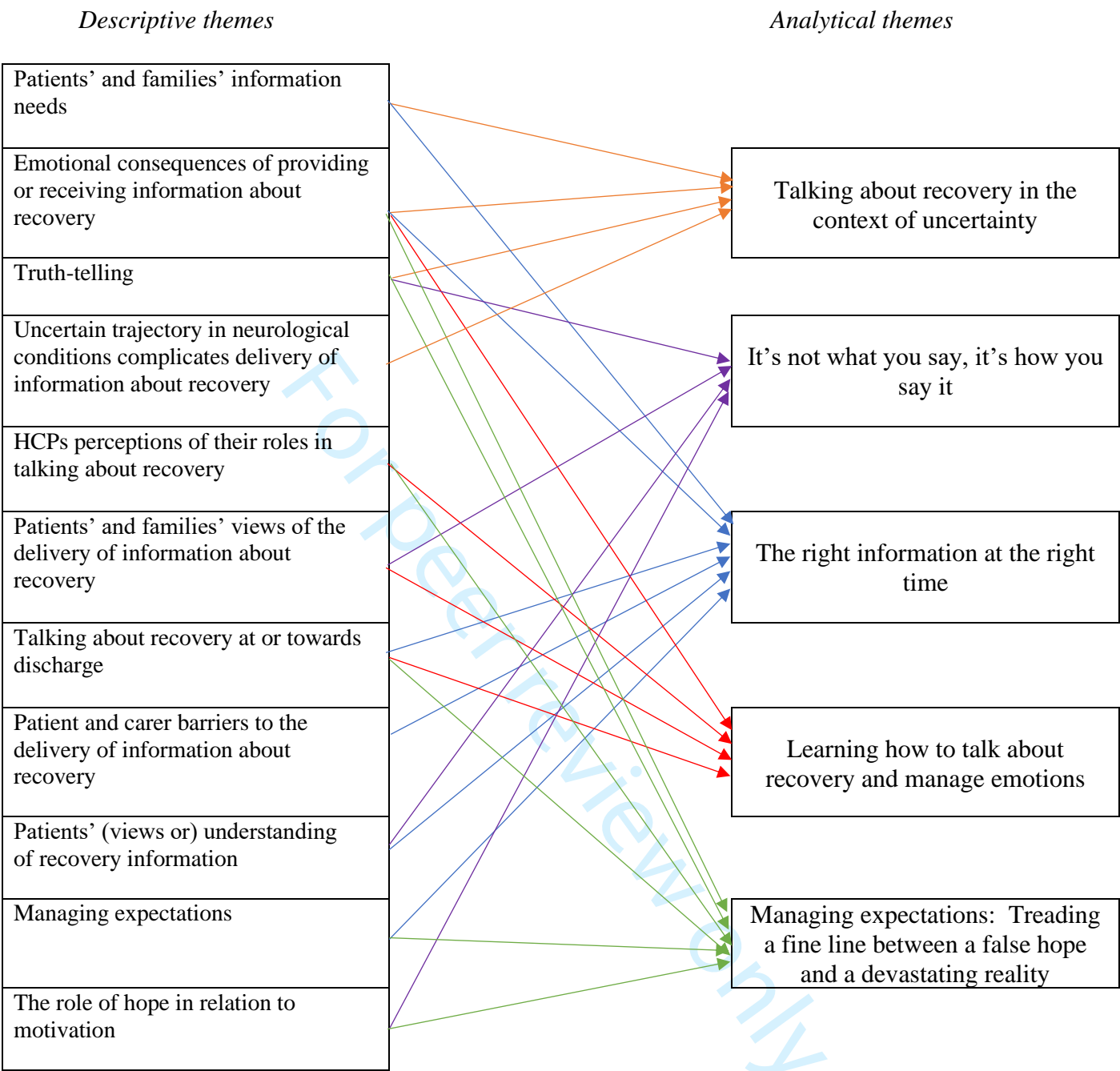


Figure 2: Descriptive and analytical themes



## Supplementary File 1 – ENTREQ checklist

No	Item	Guide and description	Page number
1	Aim	State the research question the synthesis addresses.	5
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	8
3	Approach to Searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	6
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	6
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	6
6	Electronic Search Strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	Suppl file 2
7	Study screening Methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	6
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	10-11, Tables 1, 2 and 3
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	Figure 1
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	7
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	7
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	7
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	19, Table 4
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	8
15	Software	State the computer software used, if any.	8
16	Number of reviewers	Identify who was involved in coding and analysis.	8-9
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	8
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	8-9
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	8
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	21-32
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	21-32

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**Supplementary File 2 – Example search strategy (Medline)**

- 1 (break\* adj3 news).tw.
- 2 ((difficult or bad or traumatic) adj3 news).tw.
- 3 ((communicat\* or tell\* or convey\* or disclos\* or giv\*) adj2 (diagnos\* or prognos\*)).tw.
- 4 ((inform or news) adj2 patient\*).tw.
- 5 (information provision or information exchange\* or receiving the news).tw.
- 6 (recovery adj2 (expect\* or conversation\*)).tw.
- 7 (truth-telling or truth disclosure).tw.
- 8 Truth Disclosure/
- 9 or/1-8 [breaking bad news]
- 10 (brain injur\* or head injur\* or spinal cord injur\* or spinal injur\* or multiple sclerosis or demyelinating disease\* or Parkinson\* or dementia or Alzheimer\* or vascular cognitive impair\* or lewy bod\* or huntington\* or korsako\* or motor neuron\* disease or Gehrig syndrome or amyotrophic lateral sclerosis or brain tumo?r or stroke\* or hemiplegia).tw.
- 11 (neurological adj2 (impair\* or disease\* or disorder\* or condition\*)).tw.
- 12 Brain Injuries/
- 13 Spinal Injuries/
- 14 Multiple Sclerosis/
- 15 Parkinson Disease/
- 16 Dementia/ or Dementia, Multi-Infarct/ or Dementia, Vascular/ or Frontotemporal Dementia/
- 17 Alzheimer Disease/
- 18 Amyotrophic Lateral Sclerosis/
- 19 Brain Neoplasms/
- 20 Stroke/
- 21 Hemiplegia/
- 22 or/10-21 [neurological conditions]
- 23 9 and 22
- 24 limit 23 to english language
- 25 exp animals/ not humans.sh.
- 26 24 not 25 [human only filter]
- 27 (exp Child/ or Adolescent/ or exp Infant/) not exp Adult/
- 28 26 not 27 [adult only filter]
- 29 remove duplicates from 28



# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria; participants; and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Suppl file
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	7-8





PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	9, Fig 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	11-17 (Tables 1-3)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	19 (Table 4)
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Thematic synthesis 20-31
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	31-32
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	34-35
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32-34
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data; role of funders for the systematic review).	36





## PRISMA 2009 Checklist

Page 2 of 2

For peer review only

# BMJ Open

## Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: A systematic review of qualitative literature

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-045297.R2
Article Type:	Original research
Date Submitted by the Author:	01-Apr-2021
Complete List of Authors:	Burton, Louisa-Jane; University of Leeds, Academic Unit for Ageing and Stroke Research; Bradford Teaching Hospitals NHS Foundation Trust Forster, Anne; University of Leeds, Academic Unit for Ageing and Stroke Research Johnson, Judith ; University of Leeds Faculty of Biological Sciences, School of Psychology Crocker, Thomas; Bradford Teaching Hospitals NHS Foundation Trust, Academic Unit for Ageing and Stroke Research Tyson, Sarah; The University of Manchester, Division of Nursing, Midwifery & Social Work Wray, Faye; University of Leeds, Academic Unit for Ageing and Stroke Research Clarke, David; University of Leeds, Academic Unit for Ageing and Stroke Research
<b>Primary Subject Heading</b>:	Neurology
Secondary Subject Heading:	Rehabilitation medicine, Qualitative research
Keywords:	Adult neurology < NEUROLOGY, REHABILITATION MEDICINE, Neurological injury < NEUROLOGY

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**Experiences and views of receiving and delivering information about recovery in  
acquired neurological conditions: A systematic review of qualitative literature**

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Word count: 6991

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**ABSTRACT**

**Objective:** To review and synthesise qualitative literature relating to the views, perceptions and experiences of patients with acquired neurological conditions and their caregivers about the process of receiving information about recovery; as well as the views and experiences of healthcare professionals involved in delivering this information.

**Design:** Systematic review of qualitative studies

**Data sources:** MEDLINE, Embase, AMED, CINAHL, PsycINFO, Web of Science, and the Cochrane library were searched from their inception to July 2019.

**Data extraction and synthesis:** Two reviewers extracted data from the included studies and assessed quality using an established tool. Thematic synthesis was used to synthesise the findings of included studies.

**Results:** Searches yielded 9,105 titles, with 145 retained for full-text screening. Twenty-eight studies (30 papers) from eight countries were included. Inductive analysis resulted in eleven descriptive themes, from which five analytical themes were generated: The right information at the right time; Managing expectations; It’s not what you say, it’s how you say it; Learning how to talk about recovery and manage emotions; The context of uncertainty.

**Conclusions:** Our findings highlight the inherent challenges in talking about recovery in an emotional context, where breaking bad news is a key feature. Future interventions should focus on preparing staff to meet patients’ and families’ information needs, as well as ensuring they have the skills to discuss potential recovery and break bad news compassionately and share the uncertain trajectory characteristic of acquired neurological conditions. An agreed team-based approach to talking about recovery is recommended to ensure consistency and improve the experiences of patients and their families.

## ARTICLE SUMMARY

### Strengths and limitations of this study

- This is the first systematic review of findings from qualitative studies exploring discussions about recovery in the context of acquired neurological conditions, which has integrated and contrasted the experiences and perspectives of patients, their caregivers and healthcare professionals.
- Developing an understanding of the experiences and perceptions of patients, caregivers and healthcare professionals through systematic synthesis of qualitative literature using rigorous methods can inform the development of interventions to improve practice.
- Due to the diversity of language used in the field of talking about recovery and breaking bad news, it is possible that we did not identify all titles meeting our inclusion criteria; however, all efforts were made using broad search criteria and backwards and forwards citation searching.

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**BACKGROUND**

A number of acquired conditions can cause damage to the brain, spine or peripheral nervous system, including traumatic injury, stroke and haemorrhage, with over a million survivors living in the UK alone.[1] Such disorders have a sudden onset, and if survived, can result in impairments to movement, sensation, cognition, and communication, with the potential for wide-ranging effects on an individual’s daily life. For many survivors, the road to recovery is long, and rehabilitation provided by a multidisciplinary team of doctors, nurses and therapists is recommended.[2-5]

The long-term impact of these events is characterised by uncertainty,[6] and as they participate in rehabilitation, survivors often have questions about the possibility of returning to their previous lifestyles. Such questions prompt conversations about recovery, which may involve healthcare professionals (HCPs) making and conveying predictions about recovery potential and sometimes breaking bad news.[7] Bad news has been defined as “any information that produces a negative alteration to a person's expectations about their present and future” pp. 312.[8] The term is often applied in cancer and palliative care, in relation to a life-limiting prognosis. In neurological settings however, these conversations have a somewhat different focus: some recovery is often possible and discussions may relate to whether an individual will regain functions such as movement or continence, be independent in daily life and return to activities they enjoy, or participate in their vocational or social roles. Discussions may be complicated by the inherent uncertainty in neurological recovery, and the potential impact of cognitive or communication difficulties resulting from these conditions, which can require information to be presented in different formats and increased involvement from patients’ families.[7] Despite these challenges, information about recovery is important for individuals to make future plans, and potentially adjust to life with long-term disability.

As the science in predicting recovery develops,[9-11] researchers have increasingly sought to explore and understand discussions about recovery from the perspectives of those who have experienced them, namely the patients and caregivers receiving information and the HCPs who provide it (e.g.[12]). The use of qualitative methods has generated rich and detailed understanding across a variety of contexts following diagnosis of acquired neurological conditions. However, studies are often small, condition-specific and focus on a single group (patients, caregivers, or HCPs). Synthesis of qualitative literature facilitates translation of concepts across a range of studies, making their findings accessible to a wider audience and informing clinical practice and policy.[13] This review aims to bring together and synthesise findings from qualitative studies across acquired neurological conditions, including stroke, traumatic brain injury (TBI), spinal cord injury (SCI) and brain tumour, where similar issues may be encountered, to understand how conversations about recovery are viewed and experienced by patients, their families and HCPs involved in their care. Synthesis of participants' views and experiences from this review will inform our planned development of an intervention to improve conversations about recovery after stroke and would be useful for such interventions in other acquired neurological conditions.

## **METHODS**

The systematic review protocol was prospectively registered on the International Prospective Register of Systematic Reviews (PROSPERO ref: CRD42017081922) and is reported following "Enhancing Transparency in Reporting the Synthesis of Qualitative Research" (ENTREQ) guidelines (see Supplementary File 1).[14]

### **Search strategy and data management**



Electronic databases including MEDLINE, Embase, AMED, CINAHL, PsycINFO, Web of Science and the Cochrane library, were searched from time of inception to end of July 2019. A search strategy was developed with assistance from an Information Specialist (see Supplementary File 2 for an example search). Studies were eligible if they were published in English language and:

- Reported empirical qualitative research;
- >50% of participants were either adults with a diagnosis of an acquired neurological condition (stroke, TBI, SCI, brain/central nervous system tumours), their caregivers or HCPs (including studies where HCPs worked with patients with a range of neurological conditions);
- Reported experiences, views or perceptions of giving and/ or receiving information about prognosis or recovery.

There were no restrictions according to setting or time post-diagnosis. Where a paper considered the views of HCPs working across multiple neurological conditions (rather than a specific condition, e.g. in neuro-rehabilitation), these papers were considered suitable for inclusion, as it was deemed that the views of these professionals were relevant to our research question. Previous authors of systematic reviews aiming to identify papers relating to the provision of recovery information and breaking bad news have identified challenges in keyword searching, resulting from the variety of language used in this field,[15] for example, “prognostic awareness”[16] or “difficult conversations.”[17] We aimed to be as comprehensive as possible in our selection of keywords and, to ensure literature saturation, employed backwards and forwards citation searching of included articles.

Literature search results from each database were combined, and de-duplicated in EndNote. Titles and abstracts were screened for eligibility against the inclusion criteria by the lead

author, with 20% independently screened by a second reviewer (AF). Full texts were obtained for each paper deemed to meet inclusion criteria and for those where there was uncertainty. Full text review was conducted by two independent reviewers (LB and either FW or a research colleague) using a Microsoft Access database, where reasons for exclusion were recorded. Discrepancies between reviewers were discussed and referred to a third reviewer (DJC) where agreement could not be reached.

### Quality appraisal

Critical appraisal of study quality was completed using a checklist covering the core domains of quality in qualitative research (the NICE public health guidance quality appraisal checklist[18]), which assesses fourteen domains including study design and appropriateness of qualitative methods, clarity of the study aims, data collection methods including triangulation, consideration of context, the role of the researcher, analytical methods, conclusions and ethics. Included studies were graded in three categories according to whether all or most of the checklist items were fulfilled (++), some of the items were fulfilled (+), or few or none of the items were fulfilled (-).

Two independent reviewers scored each included study according to the checklist (LB and either FW or a research colleague). The primary reviewer compared both sets of scores and discussed areas of disagreement with the second reviewer. Where consensus could not be reached, a third reviewer was consulted (JJ). In this study, quality was assessed to reveal possible limitations to included studies, rather than for the purposes of exclusion. We examined the results of lower quality studies to confirm that they did not contradict the findings of higher quality studies, and that these studies did not contribute disproportionately

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to our conclusions. This was to ensure that the synthesis results were not biased by lower quality studies and therefore lower the risk of drawing unreliable conclusions.

**Data extraction and synthesis**

Data were extracted from the selected papers, using a standardised form. Extracted data included study aims, sampling techniques and size, participant demographic information (age, gender, diagnosis), country, study setting, and methodology (data collection and analysis methods). Data were extracted from all included studies by two independent reviewers (LB and either FW or a research colleague) and compared to check agreement levels.

In addition, all text labelled as ‘results’ or ‘findings’, including participant quotations and author-generated analytical themes was extracted from included studies into qualitative data management software (QSR NVivo v10). Thematic synthesis[13] was selected for this study because it can be applied to review questions aiming to make recommendations for interventions,[19] and moves from initial line-by-line coding of data presented in individual studies, to subsequent development of descriptive, and then analytical, themes. Its detailed procedure addresses questions relating to transparency in qualitative synthesis by maintaining a clear link between the findings of primary studies and the review conclusions.[13]

In this study, extracted data were inductively free-coded line-by-line by the primary author. The codes generated were grouped and organised into descriptive themes to form a coding framework, which was subsequently reapplied to the included studies. The coded findings were then displayed in a framework matrix, to facilitate comparison of the views and experiences of HCPs, patients and caregivers; and to assess whether and how views and

experiences might vary, depending on neurological condition and participant type. Summaries describing what was important to patients, caregivers and HCPs when talking about recovery were developed for each descriptive theme and the findings of the primary studies were then considered against the review questions to develop analytical themes. This involved interpretation of study findings to develop an understanding of the range of issues that are important to participants when talking about recovery and how these affect behaviour, to make recommendations for the development of a future intervention. This development was iterative and founded upon links between the identified descriptive themes and their implications for how patients, caregivers and HCPs experience the provision and receipt of information about recovery. Preliminary results were discussed amongst the research team during the coding process, and throughout the development of themes. A draft summary of findings was prepared by LB and circulated amongst the review team, who suggested other potential interpretations. Following amendments, a final stage of reading through all included studies ensured that findings were representative of the original studies.

### **Patient and Public Involvement**

Ideas for the design of the studies making up this programme of research were presented at three groups attended by stroke survivors and caregivers (the Consumer Research Advisory Group, and two Stroke Association-run groups in Greater Manchester). Members commented on the importance of the research topic, and highlighted the need to understand the views and experiences of patients and caregivers in developing an intervention. They supported the proposals for the design and conduct of this review.

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**RESULTS**

Following removal of duplicates, the searches identified 9105 articles for title/ abstract screening (see Figure 1). Full texts of 145 papers were retrieved for review, and 30 papers reporting 28 studies were retained for inclusion. Two studies were reported in two papers each: Lefebvre & Levert[20, 21] and Wiles et al[22, 23].

[Figure 1 about here]

**Study characteristics**

The 28 included studies were conducted in eight different countries: Nine in the USA,[16, 24-31] six in the UK,[12, 17, 22, 23, 32-34] five in Australia,[35-39] three in Canada,[40-42] two in Italy,[43, 44] one each in Sweden[45] and Turkey,[46] and one in Canada and France[20, 21] (see Table 1). Included studies most frequently came from the stroke literature (n=10),[22-24, 27, 32, 33, 35, 36, 39, 45] whilst similar numbers came from TBI (n=6),[20, 21, 25, 26, 29, 30, 42] SCI (n=5),[28, 40, 43, 44, 46] and multiple neurological conditions (n=5),[12, 17, 34, 37, 41] with a minority from the brain tumour literature (n=2).[16, 38] Of the five papers considering multiple neurological conditions, four included only HCPs, who worked with patients with a range of neurological diagnoses. These included HCPs working in TBI and SCI rehabilitation,[17] occupational therapists working in neurology settings,[12] neurological physiotherapists,[34] and speech and language therapists working with patients with aphasia.[37] The latter three papers contained no further information about the diagnoses of the patients with whom the HCPs worked. The fifth paper included patients, carers and HCPs in palliative neurology, citing a range of conditions including stroke, TBI, brain tumours, amyotrophic lateral sclerosis and muscular dystrophies.[41]

Roughly equal numbers took place in the in-patient setting (n=10)[16, 17, 24, 25, 29-32, 40, 45] and community (n=11),[26-28, 33, 35, 36, 38, 39, 42, 44, 46] whilst a minority took place across multiple settings: in-patient and out-patient (n=2),[22, 23, 41] in-patient and community (n=3),[12, 20, 21, 43] and two included HCPs from a range of settings, including in-patient, out-patient and community[34, 37]. Of note, two studies were conducted in palliative care settings; one involved multiple neurological conditions (described above),[41] the other involved TBI.[30]

Five studies included data from only individuals with the condition,[28, 35, 39, 44, 46] four reported views of only caregivers,[16, 25, 31, 43] and four included perspectives of both individuals with the condition and caregivers.[26, 27, 36, 38] Seven included only HCPs, including physiotherapists,[34] occupational therapists,[12] speech and language therapists,[37] nurses,[40] doctors and nurses,[45] or a mixture of therapists,[33] or a wider mix of HCPs.[17] Three included individuals with the condition and HCPs,[22-24, 32] one included caregivers and HCPs,[29] and four included all three groups.[20, 21, 30, 41, 42] Participant demographic data from the included studies are presented in Tables 2 and 3.

In terms of data collection, most studies used semi-structured interviews (n=17),[12, 24, 25, 27, 29-31, 34, 36-39, 42-46] and three used focus groups.[20, 21, 26, 35] One used a survey,[28] and one analysed a video-taped observation.[32] Seven used mixed-methods: three employed focus groups and interviews,[17, 40, 41] one each used interviews and questionnaires,[16] observations and interviews,[22, 23] and a questionnaire and observations.[33]

Table 1: Characteristics of included studies

Authors	Neurological condition	Stated aim	Country	Service setting	Perspective	Sampling method	Sample size	Time after event	Data collection	Methodology/ Data analysis	Quality rating
Applebaum et al[16]	Brain tumour	To understand what informal caregivers of patients with malignant glioma understand about their loved one's prognosis, how they derived this information, what additional information they would like, and the existence of discrepancies in prognostic understanding between informal caregivers and patients with malignant glioma.	USA	Inpatient Neurology service at a Cancer Centre	Caregiver (Patient)	Not stated	32 (32)	In-patient	Mixed - methods. Interviews and follow-up questionnaire	Inductive thematic textual analysis	-
Becker & Kaufman[24]	Stroke	To examine illness trajectories from two vantage points, that of older persons who have had a stroke and that of physicians who care for stroke patients	USA	Community hospital	Patient Healthcare Professional	Not stated Snowball	36 20	In-patient	Semi-structured interviews	Content analysis	+
Bond et al[25]	TBI	To discover the needs of families of patients with severe traumatic brain injury during the families' experience in a neurosurgical ICU	USA	Neurological ICU	Caregiver	Convenience	7	In-patient	Interviews	Content analysis	+
Ch'ng et al[35]	Stroke	To explore long term perspectives on coping with recovery from stroke, to inform the design of psychological interventions.	Australia	Stroke support groups	Patient	Purposive	26	Community 6 months-years	Focus groups	Thematic analysis	+
Conti et al[43]	SCI	To explore the experience of caregivers of individuals with SCI analysing the final phase of hospitalization and at 6 months from discharge, to highlight their needs during hospitalization as well as emotional experiences, reactions to difficulties resulting from being back home, and subsequent positive and negative aspects related to discharge.	Italy	SCI unit	Caregiver	Purposive	11	In-patient and community	Interviews	Phenomenology: Giorgi method	++
Dams-O'Connor et al[26]	TBI	To learn about the experiences individuals with BI have in seeking and accessing healthcare (both primary and speciality care), from the 'patient' or insider perspective, in order to better understand how providers and health systems can improve care for their patients with BI	USA	Medical centres and support groups	Patient Caregiver	Convenience	44 1	Community 0.8-66.3 years	Focus groups	Content analysis	+
Danzl et al[27]	Stroke	To examine rural Appalachian Kentucky stroke survivors' and caregivers' experiences of receiving education from health care providers with the long-term goal of optimizing educational interactions and interventions for an underserved population	USA	Discharged patients from medical centres and rehab network (flyers/ mailshot)	Patient Caregiver	Convenience*	13 12	Community 1-14 years	Semi-structured interviews	Content analysis	+
Dewar[40]	SCI	To explore nurses' perceptions of their role in delivering bad news in an acute spinal cord injury unit and to describe their	Canada	Acute spinal cord unit	Healthcare professional	Convenience*	22	In-patient	Focus groups, 1 interview	Grounded theory – constant comparison method	-

		experiences, difficulties, and needs as professionals.									
El Masry et al[36]	Stroke	To explore the psychosocial aspects of the experiences, concerns, and needs of caregivers of persons following stroke.	Australia	Discharged patients from neurology unit, speech therapy department and rehab hospital	Patient Caregiver	Purposive (maximum variation and theoretical sampling)	10 20	Community >3 months	Semi-structured interviews	Interpretive phenomenological analysis: Thematic analysis	++
Garrino et al[44]	SCI	To assess SCI patients' perception of care by collecting important data to improve the current hospital and rehabilitative model of care	Italy	Discharged patients from SCU	Patient	Purposive*	21	Community >3 months post-discharge	Semi-structured interviews	Narrative approach: Content analysis	-
Gofton et al[41]	Neurological conditions	To develop a conceptual understanding of the specific characteristics of palliative care in neurology and the challenges of providing palliative care in the setting of neurological illness.	Canada	Academic medical centre	Patient Caregiver Healthcare professional	Not stated Not stated Purposive	Not stated	In-patient and Out-patient palliative	Dyadic patient/caregiver interviews Focus groups	Grounded theory – constant comparison method	+
Grainger et al[32]	Stroke	To explore the practice of bad news delivery in a specific healthcare setting.	UK	Stroke rehabilitation ward	Patient Healthcare Professional	Not stated	1 1 (part of larger study)	In-patient rehabilitation	Video-recorded interaction	Ethnography: Conversation analysis	-
Hersh[37]	Neurological conditions	To discuss speech pathologists' reports about how they discharge their clients with chronic aphasia; to explore the process of weaning in order to define its nature and raise awareness of it as a common aspect of clinical practice.	Australia	Practicing SLTs	Healthcare Professional	Not stated	20	In-patient/ Out-patient and community	Semi-structured interviews	Grounded theory	-
Kirshblum et al[28]	SCI	To determine when, by whom, and in what setting persons with neurologically complete traumatic SCI want to hear of their prognosis.	USA	Medical rehabilitation facilities	Patient	Convenience	56 (45 completed qualitative component)	Community >3 months	Online survey with open and closed questions	Thematic analysis	-
Lefebvre & Levert, 2006[42]	TBI	To investigate the experiences of individuals who had sustained a TBI, their families, the physicians and health professionals involved, from the critical care episodes and subsequent rehabilitation.	Canada	Hospital rehabilitation centres; paramedical organisation and victims association	Patient Caregiver Healthcare professional	Purposive (Maximum Variation Sampling)*	8 14 36	Community mean 2.8 years	Semi-structured interviews	Thematic analysis*	+
Lefebvre & Levert, 2012[20, 21]**	TBI	To explore the needs of individuals and their loved ones throughout the continuum of care and services, from the point of view of everyone affected by the experience of a TBI. including individuals, their loved ones, and the health care professionals involved in their care.	Canada and France	Not stated Not stated Acute care, rehabilitation	Patient Caregiver Healthcare professional	Convenience	56 34 60	Community mean=4.3 years In-patient/ community	Focus groups	Thematic content analysis	+



				or social reintegration							
Lobb et al[38]	Brain tumour	To understand patient experiences of high grade glioma and to describe their information and support needs.	Australia	Tertiary centre for neurological cancers	Patients Caregivers	Purposive	19 21	Community within 1 year of diagnosis	Semi-structured interviews	Grounded theory – constant comparison method	+
Maddern & Kneebone[39]	Stroke	To explore the experience of stroke survivors when receiving bad news (RBN) from medical practitioners	Australia	Community stroke clubs	Patients	Convenience*	10	Community 2-4 years, mean=6.2 years	Semi-structured interviews	Interpretive phenomenological analysis, Thematic analysis	+
Ozyemisci-Taziran et al[46]	SCI	To investigate the process of breaking bad news from the perspective of spinal cord injury survivors.	Turkey	Discharges from in-patient rehabilitation	Patients	Not stated	14	Community 1–19 years, mean=7.5 years	Semi-structured interviews	Content analysis	-
Peel et al[17]	Neurological conditions	To explore health professionals’ lived experiences of having difficult conversations surrounding rehabilitation potential; to explore different strategies used to support these difficult conversations; and to identify how future practice could be improved.	UK	Regional neurorehabilitation unit within an acute hospital	Healthcare professional	Convenience*	15	In-patient	One focus group; 5 individual interviews	Phenomenological approach: Thematic content analysis	+
Phillips et al[33]	Stroke	To address the seemingly neglected area of BBN within stroke care, by documenting a collaborative consultation undertaken to support this skill within a multidisciplinary community stroke rehabilitation team	UK	Multidisciplinary community stroke team for early discharge	Healthcare Professional	Self-selecting*	5	Community	Case study of consultation. Self-report questionnaire, qualitative observations	Not stated	-
Quinn et al[29]	TBI	To explore key communication preferences and practices by stakeholders (surrogates and physicians) for the outcome prognostication during goals of-care discussions for critically ill TBI patients	USA	Level-1 trauma centres	Caregiver Healthcare Professional	Purposive Purposive and snowball	16 20	In-patient	Semi-structured interviews	Content analysis	+
Rejno et al[45]	Stroke	To deepen the understanding of stroke team members’ reasoning about truth telling in end-of-life care due to acute stroke with reduced consciousness	Sweden	Combined acute and rehabilitation stroke unit teams	Healthcare Professional	Convenience sample	15	In-patient	Interviews	Content analysis	++
Schutz et al[30]	TBI	To explore how family members, nurses, and physicians experience the palliative and supportive care needs of patients with severe acute brain injury receiving care in the neuroscience intensive care unit	USA	Neuro-ICU	Patient Caregiver Healthcare Professional	Purposive	15 16 31	In-patient palliative care	Semi-structured interviews	Thematic analysis	++
Sexton[12]	Neurological conditions	To answer the question, ‘What are the experiences of occupational therapists when having bad news conversations with disabled people regarding long-term neurological disability?’.	UK	Neurological OTs	Healthcare professional	Convenience	10	In-patient and community	Semi-structured interviews	Phenomenology: Thematic analysis*	++
Soundy et al[34]	Neurological conditions	To 1) explore the meanings of the different types of hope that neurological physiotherapists give to patients to consider, 2) give greater depth to the role of hope in clinical practice, 3) present the	UK	Neurological physiotherapists	Healthcare Professional	Purposive	9	In-patient, out-patient and community Clinical	Semi-structured interviews	Categorical-content analysis	++

		dilemmas of physiotherapists hope for their patient, and 4) illustrate how different disease prognoses may influence hope						specialists and educators in one UK city			
Wiles et al[22, 23] ***	Stroke	To explore the factors, associated with physiotherapists' provision of information, that may contribute to patients' high expectations of physiotherapy	UK	3 acute Trusts	Patient Healthcare Professional	Not stated	16 26	In-patient and out-patient	Longitudinal case studies – semi-structured interviews and observations	Grounded theory: Thematic analysis	++
Zahuranec et al[31]	Stroke – intracerebral haemorrhage	To examine surrogate decision maker perspectives on provider prognostic communication after intracerebral haemorrhage	USA	5 health system/ hospital/ medical centre sites	Caregiver (Patient)	Convenience*	52 (52)	In-patient: Median day from admission to interview = 35.5	Semi-structured interviews	Thematic analysis*	+

ICU=Intensive Care Unit; TBI=Traumatic Brain Injury; SCI=Spinal Cord Injury; OT=Occupational Therapist. Participants in parentheses were recruited to the study but did not participate in the qualitative element, therefore results from these participants have not been included in the analysis. \*Inferred from author's description; \*\* A second paper from the same study was also used in the analysis, which considered only the Canadian data from healthcare professionals (n=29) and caregivers (n=19); \*\*\*A second paper from the same study was also used in the analysis, which considered the process of discharge and included only the patients who had completed data at the third time=point (n=13 patients and n=21 healthcare professionals)

Table 2: Included studies, patient and carer demographics

Authors	Perspective	Sample size	Age range	Mean age	% female
Applebaum et al[16]	Caregiver	32	Not stated	Average=50	64
Becker & Kaufman[24]	Patient*	36	48-105	Not stated	64
Bond et al[25]	Caregiver	7	41-61	Not stated	71
Ch'ng et al[35]	Patient	26	22-79	60.9	54
Conti et al[43]	Caregiver	11	28-80	57.4	73
Dams-O'Connor et al[26]	Patient	44	23-72	Not stated	58
	Caregiver	1	Not stated	Not stated	Not stated
Danzl et al[27]	Patient	13	42-89	63.4	69
	Caregiver	12	38-75	55.9	58
El Masry et al[36]	Patient	10	41-50=2; 61-70=4; 71-80=3; 81-90=1	Not stated	20
	Caregiver	20	31-40=2; 41-50=2; 51-60=3; 61-70=5; 71-80=5; 81-90=3	Not stated	80
Garrino et al[44]	Patient	21	34–63 (F); 19–70 (M)	Not stated	24
Gofton et al[41]	Patient*	Not stated	Not stated	Not stated	Not stated
	Caregiver	Not stated	Not stated	Not stated	Not stated
Grainger et al[32]	Patient*	2 (part of larger study)	Not stated	Not stated	100
Kirshblum et al[28]	Patient	56 (45 completed qualitative component)	18-30=10 31-40=17 41-50=17 50+=12	Not stated	13
Lefebvre & Levert, 2006[42]	Patient*	8	18-29=5, 30-39=1, 40-49=2	28.4	25
	Caregiver	14	18–29=3; 30–39=3; 40–49=4; 50–59=10; 60+=2	46.4	64.3
Lefebvre & Levert, 2012[20, 21]*	Patient*	56	Not stated	Not stated	30
	Caregiver	34	Not stated	Not stated	59
Lobb et al[38]	Patients	19	Not stated	Not stated	37
	Caregivers	21	30-39=2; 40-49=2; 50-9=10; 60-69=6; 70+=1	Not stated	81
Maddern & Kneebone[39]	Patients	10	61-84	63.4	30
Ozyemisci-Taziran et al[46]	Patients	14	25–57	37.2 Median=35.5	7
Quinn et al[29]	Caregiver*	16	Not stated	57	56
Schutz et al[30]	Patient*	15	Not stated	46.1	33
	Caregiver	16	Not stated	Not stated	69
Wiles et al[22, 23]**	Patient*	16	41–79	66	62.5
Zahuranec et al[31]	Caregiver	52	Not stated	Median=55	60

\*A second paper from the same study was also included, with 19 caregivers, age range=28-67, mean 50.6 years; \*\*A second paper from the same study was also included, with 13 patients of the same age range/mean age, 61.5% female.

\*Study also included healthcare professionals (see Table 3)

Table 3: Included studies, Healthcare professional demographics

Authors	Perspective	Sample size	Professional roles	Age range	% female	Years of experience in practice	Years of experience with condition
Becker & Kaufman[24]	Healthcare Professional	20	Physicians	32-78	20	Not stated	Not stated
Dewar[40]	Healthcare professional	22	Nurses	22-54	Not stated	Mean=7.4	Mean=4.6
Gofton et al[41]	Healthcare professional	Not stated	Physicians 5 nurses 6 allied health professionals (SLT, OT, PT)	Not stated	Not stated	Not stated	Not stated
Grainger et al[32]	Healthcare Professional	1 (part of larger study)	OT	Not stated	100	Not stated	Not stated
Hersh[37]	Healthcare Professional	20	SLT	Not stated	97	>20 = 12; 5-20 = 14; <5 = 4	Not stated
Lefebvre & Levert, 2006[42]	Healthcare professional	36	Nurse=16.1%; PT=9.7%; OT=6.5% SLT=3.2%; Remedial teacher=3.2%; Psychologist=6.5%; Social worker=12.9%; Special educator=6.5%; Psychosocial coordinator=3.2%; Physician=29%	Not stated	Not stated	Mean=12 <5=16.1%; 6-10=19.4%; 11-15= 35.5%; 16-20=25.8%; >20 = 6.2%	Mean=8.2 <5=32.3%; 6-10=32.3%; 11-15=25.8%; 16-20=9.7%
Lefebvre & Levert, 2012[20, 21] *	Healthcare professional	60	13 psychology/ neuropsychology; 7 OT 6 social work; 5 nursing; 4 health care aid; 3 PT; 2 kinesiology; 2 SLT; 2 clinical coordination; 2 rehabilitation counselling	Not stated	68.3	Average= 15.75	1-30

Peel et al[17]	Healthcare professional	15	Physicians, nurses, OT, PT, SLT, psychologists	Not stated	80	Not stated	<1=5, >10 years=4
Phillips et al[33]	Healthcare Professional	5	2 OT, 1 PT, 1 SLT, 1 rehabilitation assistant	Not stated	100	8-10	Not stated
Quinn et al[29]	Healthcare Professional	20	Physicians	Mean age=47	35	Not stated	Median (speciality practice)=11, range=2-40
Rejno et al[45]	Healthcare Professional	15	4 physicians, 11 nurses	Mean age=48	73	Not stated	Median: 11
Schutz et al[30]	Healthcare Professional	31	Physicians Nurses	Not stated Mean age=44.7	19 80	Median=4 Median=18	Not stated
Sexton[12]	Healthcare professional	10	OT	21-30=3, 31-40=5, 41-50=2	90	11 (range=2-27)	6.9 (range=1-13)
Soundy et al[34]	Healthcare Professional	9	PT	Mean age=43.2	100	Not stated	4-17 (median=10)
Wiles et al[22, 23]**	Healthcare Professional	26	PT	Not stated	Not stated	Not stated	Not stated

SLT=Speech and Language Therapist; OT=Occupational Therapist; PT=Physiotherapist; \*A second paper from the same study was also included, with 29 healthcare professionals of the same professions, average experience in rehabilitation=13 years, no other demographics available. \*\*A second paper from the same study was also included, with 21 PT, no other demographics available.

## Quality assessment

Table 4 details the methodological quality of included studies. Most (n=20) were scored + or ++, suggesting that all/ most or some of the criteria were met, and where there was insufficient description the conclusions would be unlikely to change. Of the eight studies deemed to be of lower quality, four lacked richness of the data presented.[27, 28, 44, 46] In four, the context from which the data were drawn was unclear,[33, 37, 40, 41] and in three, the analysis did not appear sufficiently rigorous.[33, 40, 46] In three studies, research methodology was not adequately justified,[32] data collection methods were not clearly described,[32] methods were felt to be unreliable,[40] or the links between the findings and conclusions were unclear.[28]

Table 4: Methodological quality of included studies

	<i>Appropriate</i>	<i>Not sure</i>	<i>Inappropriate</i>
<b>1 Theoretical approach: appropriateness</b>	28	0	0
	<i>Clear</i>	<i>Mixed</i>	<i>Unclear</i>
<b>2 Theoretical approach: clarity</b>	24	4	0
	<i>Defensible</i>	<i>Not sure</i>	<i>Indefensible</i>
<b>3 Research design/ methodology</b>	10	17	1
	<i>Appropriately</i>	<i>Not sure/ Inadequately reported</i>	<i>Inappropriately</i>
<b>4 Data collection</b>	14	13	1
	<i>Clearly described</i>	<i>Not described</i>	<i>Unclear</i>
<b>5 Trustworthiness: role of the researcher</b>	4	24	0
	<i>Clear</i>	<i>Not sure</i>	<i>Unclear</i>
<b>6 Trustworthiness: context</b>	15	9	4
	<i>Reliable</i>	<i>Not sure</i>	<i>Unreliable</i>
<b>7 Trustworthiness: reliable methods</b>	7	20	1
	<i>Rigorous</i>	<i>Not sure/ not reported</i>	<i>Not rigorous</i>
<b>8 Analysis: rigorous</b>	16	9	3
	<i>Rich</i>	<i>Not sure/ not reported</i>	<i>Poor</i>
<b>9 Analysis: rich data</b>	17	7	4
	<i>Reliable</i>	<i>Not sure/ not reported</i>	<i>Unreliable</i>
<b>10 Analysis: reliable</b>	9	19	0
	<i>Convincing</i>	<i>Not sure</i>	<i>Not convincing</i>
<b>11 Analysis: convincing</b>	23	5	0
	<i>Relevant</i>	<i>Partially relevant</i>	<i>Irrelevant</i>
<b>12 Analysis: relevance to aims</b>	24	4	0
	<i>Adequate</i>	<i>Not sure</i>	<i>Inadequate</i>
<b>13 Conclusions</b>	24	3	1
	<i>Appropriate</i>	<i>Not sure/ not reported</i>	<i>Inappropriate</i>
<b>14 Ethics</b>	19	9	0
	++	+	-
<b>Overall assessment</b>	7	13	8

## Thematic synthesis

Eleven descriptive themes were generated from the synthesis, and gave rise to five analytical themes,[13] reflecting patient, caregiver and HCPs' experiences of receiving and providing information about recovery. Descriptive themes are outlined in Figure 2; the five analytical themes are considered in detail below:

[Figure 2 about here]

### *The right information at the right time*

In general, patients and families across studies wanted to receive information about their diagnosis and recovery prognosis from their treating medical teams.[20, 21, 24, 25, 43, 44] This usually included information about the nature of the patient's condition, the cause, available treatments, and the prognosis or long-term prospects. However, there was some variation in what was deemed to be the 'right' information across conditions and individuals. Patients with SCI particularly wanted clear information about their diagnosis,[43, 44] whilst patients with stroke and TBI commonly wanted information about their recovery potential, including how long this would take and their long-term outcome.[20, 21, 24, 25] In contrast, some patients with tumours did not wish to receive prognostic information (usually in relation to a life-limiting condition):[16, 38]

*[...] when we met with the doctor, it seemed she wanted to reveal to us where we stood, and I interrupted her, and said that I really do not want to, I cannot hear that so please do not share that with me."* Caregiver, brain tumour[16]

Overall, a source of dissatisfaction for patients and caregivers across numerous studies was a feeling that they did not receive enough information from their healthcare teams.[20, 21, 26, 27, 29, 35, 36, 38, 39, 42, 43, 46] Complaints included HCPs not being proactive in providing information,[27, 42] or not providing timely information.[20, 21, 26, 39] Patients



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and caregivers described negative emotions associated with not receiving information including frustration,[20, 21, 29, 43] worry,[39] caregiver stress,[43] delay in acceptance and adjustment,[42] and decreased trust in, and poorer relationships with, their treating HCPs.[29, 42] Consistency in approach and language across different HCPs was viewed as essential, with concerns raised when different professionals provided incongruous information.[25, 29, 31]

The timing of information provision was also a key concern for patients and caregivers. In the acute phase after TBI, stroke or SCI, e.g. in the emergency room, information was often provided to families, due to the medical status of the patient. However, even where patients were medically stable, the nature of an unexpected neurological event or diagnosis meant that they or their families often felt unable to understand or retain information effectively in the early period after the event, due to their emotional state of mind, i.e. feeling overwhelmed, or in shock:[20, 21, 26, 27, 35, 38, 42]

*“In [the hospital], my wife was away for a moment when the nurses were doing their rounds, but my mom was there. And they gave her a bunch of handouts. . . And I think they may have explained a little bit about brain injury. But my mom wasn’t quite in the head-space to remember all of it at the time. [...]”* Patient with TBI[26]

Some patients and caregivers accepted these limitations and described how they wanted information to be repeated at different time-points.[26] For HCPs however, this presented a challenge: they were aware of these difficulties,[20, 21, 40, 42] but feared complaints from patients and caregivers who felt that information was not satisfactorily provided.[42] Suggested strategies to manage this situation included repetition of information at different times,[26, 27, 42] provision of written materials,[26] and providing staff contact details for patients and families to contact if they had questions at a later time.[26]

HCPs agreed that the timing of information about recovery potential needed to be right for the individual patient and caregiver, suggesting that they needed to be ‘ready’ to hear it,[12] or they risked causing anger or distress.[33] Some studies, particularly those involving stroke survivors, suggested that some patients could reject or deny information about recovery provided when they were not ready to hear it, particularly where it was perceived to be negative and challenged their hopes of returning to their previous lifestyle:[22, 23, 33, 39, 46]

*“I just thought, I’ll be all right, I’ll be all right... the people told me that you will get aphasia and that you’re going to have that for the rest of your life and I thought, yeah, I’ll be over that in a couple of weeks’ time, and never did [get over it].”* Patient with stroke[39]

Some HCPs felt that the most important time to provide information was during rehabilitation (although of note, no studies included the rehabilitation of patients with brain tumours), when patients receive therapy to help them re-gain their independence, with some suggesting ‘drip-feeding’ it over time,[17, 37, 40] or providing it in the context of a formal meeting:[17]

*“In the back of your mind, you’ve got some rough plan of “I don’t think she is really going to ever get functional verbal speech” so you do your other stuff along the way to try and bring them to that point as well.”* Speech & Language Therapist[37]

In some cases, the practicalities of discharge forced therapists to discuss recovery towards the end of rehabilitation,[22, 23] particularly where a patients’ home environment was deemed unsuitable or their care needs had increased:[12, 32]

*“The patient perhaps isn’t safe to go home anymore ... and we were recommending placement, and that’s always hard to discuss with people.”* Occupational Therapist, In-patient neurology[12]

Where patients and particularly caregivers felt they didn’t receive the right information about recovery from HCPs, they sought it from other sources.[16, 20, 21, 46] Most commonly,

alternative sources included use of the internet,[16, 17, 20, 21, 46] and books and newspapers.[20, 21, 34] Human sources of information included fellow patients and their families,[17, 46] and skilled relatives or friends.[20, 21, 39, 46] Occasionally, HCPs expressed concern about the use of additional sources, worrying that information could provide false hope, particularly where the information did not pertain to the individual's specific case.[17, 34]

*Managing expectations: Treading a fine line between false hope and a devastating reality*

This theme relates only to studies in TBI, SCI, stroke and general neurology settings; none of the included studies considered rehabilitation after brain tumour.

Although HCPs felt that during rehabilitation was the best time to discuss recovery potential, this was sometimes problematic. During rehabilitation, patients were mostly engaged in therapy and motivated to work hard. Whilst HCPs endeavoured to be realistic in the information they provided, they were aware that receiving potentially 'bad news' about how much (or how little) a patient might achieve in the long-term could be distressing and demotivating. As a result, they were concerned about the impact negative information could have on patients' mood, hope and, subsequently motivation to participate in rehabilitation;[12, 17, 24, 33, 34, 40] a feeling which was echoed by some patient and caregiver participants.[39] HCPs feared that a loss of motivation could result in a negative prediction becoming a self-fulfilling prophecy:

*"I just don't want to sort of squash their hope ... they sort of give up a lot and also they don't maintain their home exercise programme."* Occupational Therapist, community rehabilitation[43]

These fears could result in HCPs being unwilling or hesitating to discuss recovery with patients and families.[12, 24]

At the opposite end of the spectrum, HCPs also feared that a failure to manage patients' and families' expectations about recovery and provide realistic information could foster 'false hope,' and allow patients' and families' to maintain expectations of a return to life as they had experienced it before their neurological event.[12, 22, 23, 29, 30, 34, 42] They worried that patients, and their families, would be disappointed or distressed if their hopes for recovery were not realised.[22, 23, 29, 34] As a result, HCPs knew they must provide some realistic information to manage patients' and carers' expectations, but expressed that they must do so in a way that nurtured their patients' hope and motivation; this was presented as a careful and challenging balance:[17, 22, 23, 33, 34, 37, 40]

*"You wouldn't want to give them too high hopes, but then you also want to encourage them [...]"* Neurological physiotherapist[34]

HCPs described several strategies they used to manage the expectations of patients and their caregivers. In the acute phase, they could provide written information about the role of rehabilitation and what could be provided by their service.[17] During rehabilitation, therapists described how realistic goal-setting[12, 34, 37] and repetition of information about recovery in different forms (written, via keyworker or outreach service)[17] could help to manage expectations about what it might be possible to achieve. Where expectations were effectively managed, HCPs described benefits in enabling carers to plan for the future[12] and in facilitating discharge;[37] however where patients maintained what HCPs deemed to be unrealistic hopes for recovery, they felt this limited adjustment to disability.[22, 23]

Underlying discussions about recovery appeared to be an assumption made by patients that they would make a full recovery, and that their main route to recovery was through

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rehabilitation. Where this was the case, they perceived discharge as an end to their recovery, and expressed disappointment if it occurred before their recovery expectations were met.[22, 23] In contrast, HCPs understood recovery as a long-term process, with its conclusion likely involving adaptations to a patient’s previous lifestyle. In a minority of studies however, it wasn’t simply the outcome of rehabilitation about which HCPs and patients were observed to have incongruous ideas, but also their understanding of the process. Whilst HCPs described that what could be achieved through therapy was mediated by spontaneous neurological recovery, only two studies described how this was conveyed to patients and families,[22-24] and this concept was rarely mentioned by patient and family participants.[22, 23, 27] Patients and families therefore, placed much emphasis on patients’ motivation and effort within rehabilitation, which could result in feelings of failure if their expected level of recovery was not achieved.[20, 21] Rather than discussing the complexities of rehabilitation with patients and families, HCPs attempted to bring patients’ and families’ expectations and perspectives about recovery closer to their own so that they were ‘on the same page’[30, 32] Strategies employed by HCPs at discharge when patients felt they had not achieved their expected recovery included negotiation of a finite number of treatment sessions or the use of objective measures to demonstrate to the patient that they were no longer making progress and thus persuade them that more therapy would not be beneficial to their recovery.[22, 23, 37]

*Its not what you say, its how you say it*

Where HCPs feared both giving false optimism and destroying hope, patients and families described how important hope was to them.[16] Where information about recovery was provided, patients and families felt that HCPs should deliver it with compassion and

empathy,[20, 21, 27-29, 38, 39, 46] as well as positivity, allowing them to maintain hope and motivation:[20, 21, 28, 30, 36, 38, 39, 46]

*"I think they need to be more in empathy with the patient rather than just a number."*

Patient with stroke[39]

They wanted positive messages, including a focus on the function the patient retained, rather than what they had lost:[28, 38]

*"I would prefer the initial statement to be addressing the positive aspect of the condition. e.g. 'you are capable of doing almost all you did before the accident'."*

Patient with SCI[28]

This presentation of 'good news' alongside bad news was observed,[32] and also acknowledged as a strategy by some HCPs.[40] Patients and caregivers expressed a need to feel listened to and understood, with their distress acknowledged.[26, 27, 39, 46] A private setting for information provision was important, and patients valued being able to choose whether their families were present or not.[28, 46] Sometimes, however, patients and caregivers felt HCPs were too negative in the messages they gave, resulting in distress, anxiety, fear or anger.[30, 36] Where bad experiences were recounted, they involved receiving incongruous information from different HCPs,[25, 29, 31] overhearing information,[46] not being given an opportunity to ask questions,[20, 21, 39, 46] or the use of complex medical terminology, which limited their understanding of the information.[20, 21, 31]

Patients and caregivers also described a desire for truthful and honest information about recovery,[20, 21, 25, 28-30] and HCPs felt that telling the truth was important to build relationships, gain families' trust and maintain their own credibility:[40, 45]

*"I can take the bad news. Just don't tell us things that are not true and think that we need to hear happy things."* Caregiver, TBI[25]

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For HCPs, a consistent approach to conveying information could help patients to process and understand what had happened to them, accept residual disability and adjust to necessary lifestyle changes.[17, 34, 37] It was also crucial to developing a trusting relationship between patients, their families and HCPs.[20, 21, 42] The use of inconsistent language between HCPs and the expression of different viewpoints could have negative effects on caregivers, including causing distress and confusion,[31] causing them to doubt the truth of what HCPs were telling them,[25, 31] triggering arguments amongst families,[25] and resulting in stress and anxiety in decision-making.[29, 31] In some studies, participants suggested having one key contact in the patient’s family and one on the healthcare team, or providing written information, could aid consistency.[17, 20, 21, 25]

*Learning how to talk about recovery and manage emotions*

Most professionals described a role in talking about recovery (with the exception of brain tumours; no included studies involved HCPs working with patients with brain tumour), and in breaking bad news, including physicians and therapists,[12, 17, 24, 30, 33, 37] although none advocated a team approach. Nurses did not take outright ownership of this role, choosing to defer to physicians or therapists,[30, 40] although some described how the round-the-clock nature of their work meant they were well-placed and available to answer patients’ questions when information provided by other HCPs had had time to ‘sink in’.[40]

Although therapists described a role in talking about recovery, they described lacking sufficient training or confidence, worried patients would not listen to them and felt uncomfortable answering questions outside of their expertise.[12, 17, 33] In terms of the knowledge and skills required, therapists and nurses felt communication skills were important to effectively discuss recovery with patients and families, as well as knowledge about, and

ability to predict, potential outcomes.[12, 17, 33, 34, 40] Most felt that learning to break bad news was experience-based, rather than provided via formal training,[12, 17] although some expressed an unfulfilled need for training.[12, 17, 33, 42] Where training was desired, therapists wanted it to be led by experienced colleagues, and suggested techniques such as role-play, supervision and debriefing, and reflective practice. Provision of staff support groups[12] and access to clinical guidelines were also felt to be important.[17] In terms of content, therapists wanted training to include the grieving process and breaking bad news.[17] Access to training was not discussed by physicians in the included studies, perhaps because such training is now commonly provided as part of medical education.

Where HCPs (therapists, nurses and physicians) talked about their experiences delivering information about recovery, and particularly, breaking bad news, they often described an emotional cost. Their emotional reactions ranged from awkwardness and discomfort, to worry and stress, as well as feelings of responsibility or failure:[12, 17, 22, 23, 40-42]

*“We are dealing with long term disability and we’re almost dealing with the acute stages of anger and coming to terms, [it] can be really emotionally hard for the therapist as well.”* HCP, in-patient neurorehabilitation[17]

*“I wonder if there is a sense ... almost that you have failed the patient.”*

Occupational Therapist, in-patient neurology[12]

HCPs described that these conversations became easier with experience and identified reflective practice and debriefing with team members as ways to manage their emotions.[12, 17, 40]

Patients and caregivers also described their emotional responses to discussions about recovery. This was often related to receiving ‘bad news’, and included shock (at diagnosis),[38, 42] fear,[39] anger,[39, 46] distress,[35, 39, 46] and anxiety.[35] In some



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cases, the way that information about recovery or bad news was presented provoked a negative emotional response, for example, where patients felt the HCPs provided the information in a rushed or patronising manner, they could experience anger or anxiety.[39] In addition to delivering information about recovery, HCPs described a role in managing the resulting emotional reactions of patients and families.[17, 22, 23, 33, 40, 42, 45] They described how strategies such as detaching themselves from the situation and talking about their own feelings could help,[42] however some described withholding information or avoiding having conversations with patients or families to limit their emotional response.[42, 45]

*Talking about recovery in the context of uncertainty*

Before being able to convey information about recovery and prognosis to patients and their families, and thus meet their information needs, HCPs must feel able to make predictions about how the trajectory of an acquired neurological condition might progress for a specific individual. To do this, some described using clinical evidence or results of medical investigations, whilst others relied on their previous clinical experience; however they often felt that outcomes were still uncertain.[22-24, 34, 41] Across studies, HCPs discussed how uncertainty impacted their ability and willingness to share their predictions with patients and their families. They described how, although they might have a hunch or an instinct about how much recovery a patient was likely to achieve based on their previous experience, it was not always possible to generalise across cases, and they might encounter exceptions:[24, 34, 37]

*“I do find that most families, or the person themselves wants to know how much is this going to improve . . . how quickly that's going to happen? And I usually say*

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3       *“well, I don't know, everybody is different” and in my own mind I have probably*  
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5       *already got a gut feeling of how much change they are going to make, as in actual*  
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7       *change on testing . . . but it is not usually something that I would verbalise . . .*  
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9       *because you do get the surprises.”* Speech and Language Therapist[37]  
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13 HCPs dealt with this uncertainty in different ways. Many were afraid to convey predictions  
14 about recovery to patients and their families for fear of being wrong, and therefore giving  
15 false hope, causing disappointment and anger if their predictions did not come to pass; or  
16 quashing hope unnecessarily.[22, 23, 40-42] They feared that the information provided  
17 would be ‘used against them’ by patients and families and worried about damaging  
18 relationships.[22, 23, 29, 42] As a result, some HCPs described how they might avoid or  
19 delay providing information about recovery;[22, 23, 30, 33, 37, 42] which did not go  
20 unnoticed by patients.[42, 44] Many provided vague information or made attempts to convey  
21 the uncertainty they faced:[20-24, 29, 37, 42]  
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34       *“The prognosis is never certain, and when you don't know, you have to tell them you*  
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36       *don't know.”* HCP, TBI[20]  
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39       *“I just own it. I just say I'm not sure[...]* Usually I'll have a hunch, that it is going to  
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41       *go one way or the other, but I readily and openly cop to not being sure and not*  
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43       *knowing.”* Physician, Critically-ill TBI[29]  
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46 Some HCPs felt that sharing their uncertainty could instil realism in patients and families,  
47 thus avoiding false hope, but could help patients to maintain the hope that they needed to  
48 keep them engaged and motivated in rehabilitation.[24, 34, 37]  
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52 The extent to which patients and their families accepted the uncertainty presented to them  
53 varied across individuals. Whilst some were able to accept it,[22-24, 31, 44] others found  
54 uncertainty resulted in feelings of frustration, worry and confusion:[20, 21, 31, 36, 42, 43]  
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*“I don’t know what he is going to be able to do. It made me anxious I guess is probably the best way to describe it. I wanted answers and they really were not able to give me answers.”* Caregiver of patient with intracerebral haemorrhage[31]

The inability to see what the future might hold could make them feel helpless and impotent; the trajectory appeared outside of their control, and the endpoint was unclear.[24, 43]

However, some families did find hope in the uncertainty presented to them.[30, 31] The ‘not knowing’ of what may occur gave them space to hope for a positive outcome. Some described sympathy for the HCPs, who they believed were trying their best in an uncertain situation:[44]

*“Doctors never committed themselves by saying you will never walk again. However, the poor things really didn’t know what to say.”* Patient with SCI[44]

From the perspective of HCPs, some felt that patients and families generally could understand the uncertainty they were facing as professionals, whilst others accepted that uncertainty could cause frustration or distress.[37, 42]

**DISCUSSION**

This study demonstrates the difficulties inherent in talking about recovery after neurological events. Although patients and caregivers desire more information about an individual’s potential for recovery, a triad of factors impact HCPs’ efforts to meet these needs, namely the uncertain trajectory of recovery, a desire to maintain patients’ hope and motivation in rehabilitation, and typically an absence of training to discuss recovery and break bad news. Where information is provided, patients and caregivers emphasise that it should be delivered honestly, with kindness and compassion, and most of all, positivity.

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3 It is unsurprising that our findings indicate that patients and caregivers report unmet needs for  
4 information: This finding is common within the neurological literature.[47-50] However,  
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6 our findings suggest that it may be unclear whether information provision did not occur or  
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8 whether information was provided but patients and caregivers were unable to retain it, due to  
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10 the shock of diagnosis, or cognitive or communication problems resulting from neurological  
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12 damage, or to understand it; due to complexities in medical language. Future studies should  
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14 utilise both interviews and observations of clinical practice to ascertain this. The timing of  
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16 information provision is also important and past research has recognised how patients' and  
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18 families' information needs may change. For example, the 'Timing it right' framework  
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20 describes how caregivers of patients with stroke are initially concerned with information  
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22 about whether the patient's condition is life-threatening, and following stabilisation of their  
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24 medical condition, thoughts turn to whether and how much functional recovery is  
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26 possible.[51] Our findings suggest that HCPs should be encouraged to consider proactively  
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28 asking patients and families whether and what types of information they would prefer at  
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30 different times before providing it. However, they should be aware of potential difficulties in  
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32 absorbing or retaining information, particularly when provided in acute settings, and  
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34 therefore consider providing written materials or contact details of HCPs where appropriate.  
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37 Our study highlights the need for consistency in the communication of recovery information  
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39 to patients and families, with poorer experiences reported following receipt of different  
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41 information from different HCPs. Although not unexpected in the context of an uncertain  
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43 recovery trajectory, it is imperative that multidisciplinary team members are clear about their  
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45 roles in discussing recovery and that the messages they provide correspond with those of their  
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47 colleagues. Whilst prognostication is traditionally seen as the role of doctors and this is  
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49 appropriate particularly where disease is life-limiting disease, our study has highlighted the  
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51 key role that other team members play in discussing recovery in neurorehabilitation.  
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Therapists contribute specific knowledge about functional recovery and their roles in therapy provision and goal-setting require them to manage expectations about what can be achieved through rehabilitation. Nurses are also well-placed to answer patients’ questions about recovery, although they may defer questions to other professionals,[40] and this could potentially result in missed opportunities for communication or increase patients’ anxiety. Nurses’ concerns about discussing recovery with patients with neurological conditions and their families have previously been documented,[40, 52] despite an identified role in providing information to help patients and families make sense of the impact of their event to facilitate adjustment.[53] Future interventions should encourage a team-based approach to talking about recovery, and consider ways to ensure that individual conversations are appropriately shared via documentation or team meetings.

HCPs’ concerns about destroying hope when trying to instil realistic expectations were evident in our study, demonstrating their awareness of the psychological impact that information about recovery, and the way it is presented, can have on patients and caregivers. Our findings highlight patients’ and families’ desire for empathetic and compassionate delivery of information, particularly when receiving bad news. Approaches to communicating bad news are available,[54, 55] providing recommendations, including how to prepare a patient and manage their subsequent emotions. Training incorporating these models using techniques such as role play and group discussions, have been demonstrated to be effective in increasing clinicians’ confidence[56, 57] and patient satisfaction.[58] Given the roles played by therapists in talking about recovery in neurological settings identified by our review, it is perhaps surprising that only one study recognised the use of such models in their training,[33] and they described breaking bad news as a skill they were expected to have but learned only through experience. Future training interventions would benefit from inclusion of specific communication skills to help therapists manage conversations about

recovery in ways which meet the needs of patients and their families. The role of experiential learning should be supported through the inclusion of training or shadowing opportunities specific to recovery conversations for newly qualified therapists or those new to neurological settings.

The emotional cost to HCPs involved in discussing recovery has also been highlighted in our study. Some research has explored the emotional well-being of HCPs working in neurological rehabilitation, and it has been suggested that the frequent undertaking of emotional conversations with patients (who might display behavioural symptoms and have interpersonal problems) and their families, could be linked to occupational stress and burnout.[59-61] Identified solutions to such stress for HCPs include clinical supervision, organisational and professional support and strong team relationships,[59, 62] some of which were also identified as facilitators of talking about recovery in our study. Future interventions should promote awareness of these issues and encourage practices such as debriefing and reflective practice to help HCPs manage their emotions.

### **Strengths and limitations**

To our knowledge, this is the first systematic review to synthesise patients', caregivers' and HCPs' views and experiences of talking about recovery in acquired neurological conditions. The synthesis of qualitative studies using rigorous methods has allowed us to understand and synthesise the perspectives of the three groups of participants in recovery conversations, which is key to developing an intervention which is acceptable to, and meets the needs of, all parties and can be effectively implemented into clinical practice.

A limitation of our study is that the validity and relevance of our findings are dependent on the quality and reporting of the included studies. Appraising the quality of qualitative

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research is a contentious issue, both in terms of whether and how it should be completed.[63]  
We employed a widely-used tool, which was designed to assess the quality of evidence to  
make recommendations for inclusion in public health guidance.[18] Although we did not  
utilise quality assessment to exclude studies from our review, all the included studies were  
considered worthy of inclusion, as they made a valuable contribution to the synthesis.

Although we were able to compare and contrast the findings of papers considering the views  
of patients, carers and HCPs with a single acquired neurological condition, we included five  
papers, which reported the views and experiences of HCPs, who worked with patients with a  
range of neurological diagnoses. This precluded further exploration relating to specific  
conditions. It may also be possible that HCPs who had contact with patients with both  
acquired and progressive conditions may have had slightly different views about talking to  
patients and carers about recovery, than those solely working with those with acquired  
conditions. However, such is the nature of clinical training that it is likely that the HCP  
participants in all studies may have had previous experiences in other clinical areas which  
may have informed their views.

We employed a robust search strategy with backwards and forwards citation searching to  
identify articles for inclusion, however the use of inconsistent terminology in this field, and in  
qualitative research in general, means that some eligible titles may have been missed.  
Additionally, the inclusion of only studies published in English may have resulted in the  
omission of the experiences of patients, caregivers and HCPs reported in different languages.

**Implications for future research**

Our study has implications for the design of interventions to improve conversations about  
recovery in acquired neurological conditions. However, although research has explored

views and perceptions of discussions about recovery, there is little empirical evidence about the effects of interventions. Future research and the evaluation of interventions should also consider whether talking about recovery in a structured way can impact outcomes such as patient satisfaction, mood and adjustment to disability when compared with standard care, and whether specific training for staff could improve confidence and experiences.

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**Data availability:** The data extracted from papers included in the systematic are already published and in the public domain.



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**Figures:**

Figure 1: PRISMA flow diagram of study selection

Figure 2: Descriptive and analytical themes

Figure 1: PRISMA flow diagram of study selection

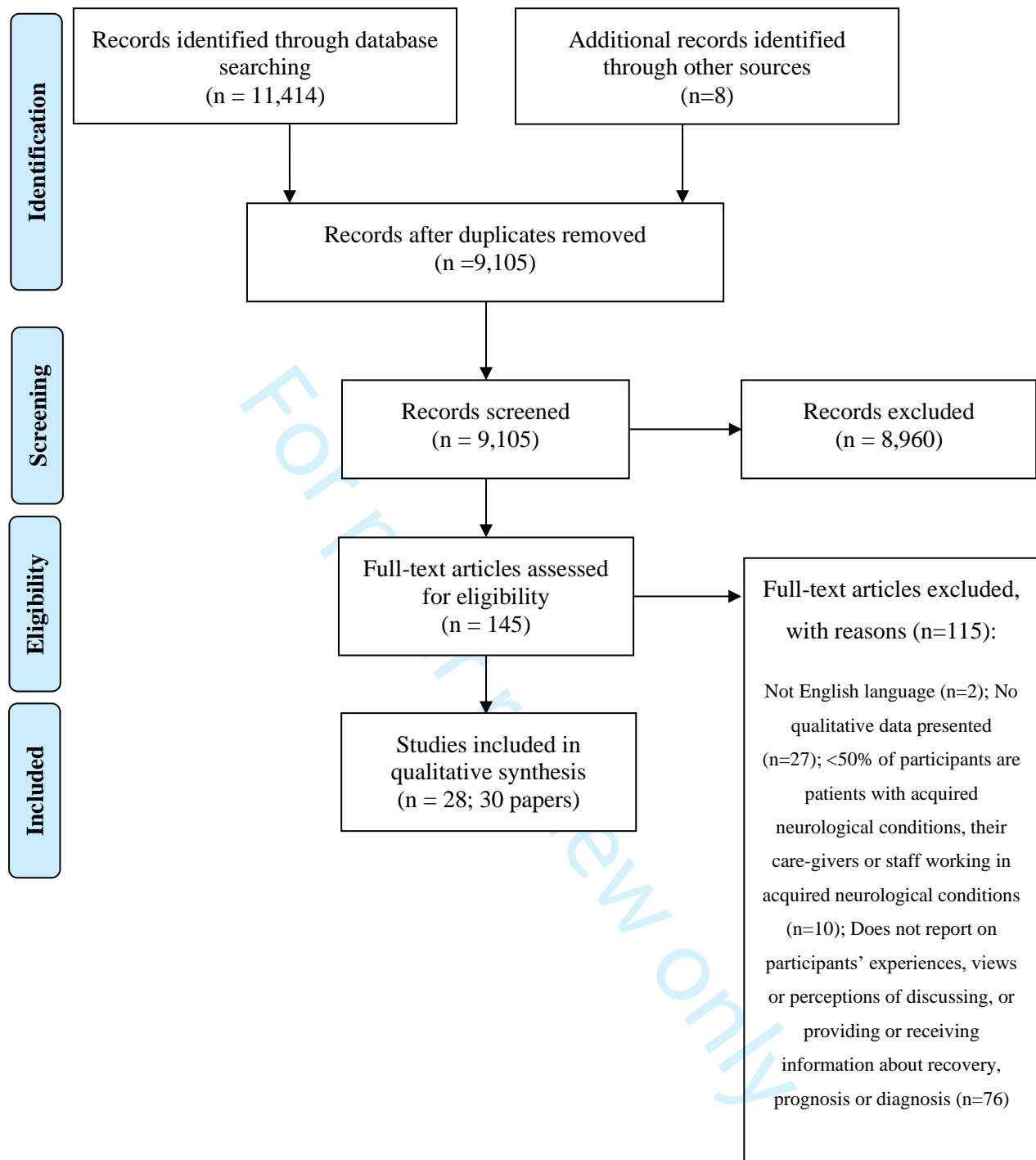
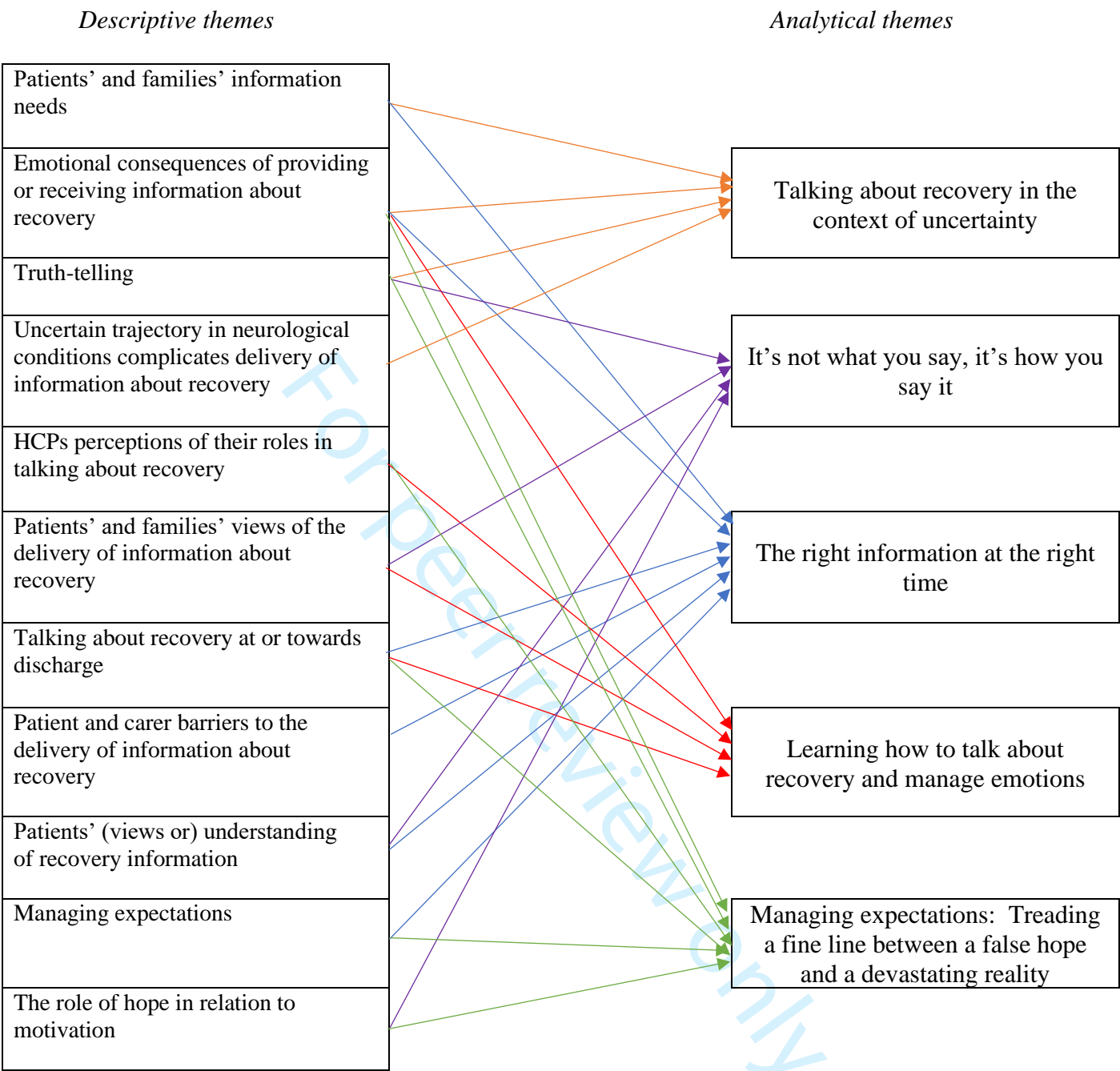




Figure 2: Descriptive and analytical themes



## Supplementary File 1 – ENTREQ checklist

No	Item	Guide and description	Page number
1	Aim	State the research question the synthesis addresses.	5
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	8
3	Approach to Searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	6
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	6
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	6
6	Electronic Search Strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	Suppl file 2
7	Study screening Methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	6
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	10-11, Tables 1, 2 and 3
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	Figure 1
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	7
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	7
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	7
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	19, Table 4
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	8
15	Software	State the computer software used, if any.	8
16	Number of reviewers	Identify who was involved in coding and analysis.	8-9
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	8
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	8-9
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	8
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	21-32
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	21-32

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**Supplementary File 2 – Example search strategy (Medline)**

- 1 (break\* adj3 news).tw.
- 2 ((difficult or bad or traumatic) adj3 news).tw.
- 3 ((communicat\* or tell\* or convey\* or disclos\* or giv\*) adj2 (diagnos\* or prognos\*)).tw.
- 4 ((inform or news) adj2 patient\*).tw.
- 5 (information provision or information exchange\* or receiving the news).tw.
- 6 (recovery adj2 (expect\* or conversation\*)).tw.
- 7 (truth-telling or truth disclosure).tw.
- 8 Truth Disclosure/
- 9 or/1-8 [breaking bad news]
- 10 (brain injur\* or head injur\* or spinal cord injur\* or spinal injur\* or multiple sclerosis or demyelinating disease\* or Parkinson\* or dementia or Alzheimer\* or vascular cognitive impair\* or lewy bod\* or huntington\* or korsako\* or motor neuron\* disease or Gehrig syndrome or amyotrophic lateral sclerosis or brain tumo?r or stroke\* or hemiplegia).tw.
- 11 (neurological adj2 (impair\* or disease\* or disorder\* or condition\*)).tw.
- 12 Brain Injuries/
- 13 Spinal Injuries/
- 14 Multiple Sclerosis/
- 15 Parkinson Disease/
- 16 Dementia/ or Dementia, Multi-Infarct/ or Dementia, Vascular/ or Frontotemporal Dementia/
- 17 Alzheimer Disease/
- 18 Amyotrophic Lateral Sclerosis/
- 19 Brain Neoplasms/
- 20 Stroke/
- 21 Hemiplegia/
- 22 or/10-21 [neurological conditions]
- 23 9 and 22
- 24 limit 23 to english language
- 25 exp animals/ not humans.sh.
- 26 24 not 25 [human only filter]
- 27 (exp Child/ or Adolescent/ or exp Infant/) not exp Adult/
- 28 26 not 27 [adult only filter]
- 29 remove duplicates from 28



# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria; participants; and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Suppl file
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	7-8



PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	9, Fig 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	11-17 (Tables 1-3)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	19 (Table 4)
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Thematic synthesis 20-31
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	31-32
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	34-35
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32-34
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data; role of funders for the systematic review).	36

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097



## PRISMA 2009 Checklist

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For peer review only